The Representation of Terminally Ill Cancer Patients: a Transitivity Analysis of Advice and Interview Texts

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by

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ABSTRACT

In recent years there has been much research into the roles of doctor and patient and the nature of the interaction between them. Research has shown that certain identifiable and fixed roles are evident within the doctor-patient relationship. However, these roles are perhaps less 'fixed' than previously thought and it can be argued that the roles and relationship have evolved over time, with significant changes taking place more recently.

Previously, the traditional doctor and patient roles and relationship were characterised by an imbalance of knowledge and power. This was largely influenced by the biomedical model and the strict parameters of the medical gaze. More recently, there has been a more patient-centred and person-centred approach to medical interaction. This has led to changes in the doctor-patient relationship which appear to be reconfiguring the medical gaze to be more inclusive of the patient, who has increased knowledge and power. This presents an evolution from one model to another very different model of medical experience.

In tandem with this there has also been greater emphasis within medical discourse upon two key areas which are of relevance to the current study. The first of these has been upon the provision of adequate advice for patients, while the second concerns the attention to and inclusion of the patient voice within this advice. Although this change in emphasis and changes in the doctor-patient relationship may be found in medical discourse in general, this study confines itself to one particular context of health; namely that of terminal cancer. Furthermore, this context of terminal illness can be regarded as one which, in comparison to other health situations, is a relatively recent focal point within medical discourse and advice and one in which both doctors and patients can feel ill-equipped.

The purpose of this study is to examine the key roles and relationships and how these entities tend to behave in medical texts. This includes doctors, patient and significant others involved in the medical situation such as family and friends. Of particular interest to this study is the way in which these roles and relationships have developed recently and how evident this may be in medical discourse.

In particular, the study aims to consider how medical experience is represented in text by analysing the linguistic choices made, through which experience is communicated. In order to achieve this detailed text analysis has been conducted, employing Halliday's system of Functional Grammar. The application of this particular analytical system can reveal how meaning in text is constructed by grammar. Within this system, the model of Transitivity in particular has been used to reveal how people are represented within the data and how key entities tend to behave. The data under analysis originates from two different sources. The first of these can be regarded as the 'voice of medicine', with texts taken from medical advice websites. The second source is the 'patient voice', using patient interviews taken from a

database of patient experience. The focus upon two different sources can help to determine whether or not the experience of terminal illness is represented differently by these two sets of voices.

This analysis shows that changes in the roles of doctors, patient and significant others are apparent and that there has been a discernible shift in the balance of power. Regarding the linguistic choices of each 'voice', there are notable similarities between the two data sets but also certain, predictable or otherwise, differences. Overall, the study shows how changes within medical models of practice are both evident in and constructed by medical discourse. These findings form the basis of a closer inspection of how the writers' and speakers' linguistic choices represent the experience of terminal illness for the reader/listener. In essence, the grammatical patterns found can reveal something of the world of terminal illness from two different, but not necessarily opposing, vantage points within that world and can help to uncover and examine certain assumptions therein.

DECLARATION

This work is original and has not been submitted previously in support of any degree, qualification or course.

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Contents

Chapter One: Introduction

The roles of doctors and patients and their relationship have received increasing attention within medical research which has acknowledged and explored the significance of how these roles can influence the experience of medical encounters from both sides of the relationship (Davis, 1978; Bennet, 1979; Browne et al., 1984; Ong et al., 1995; Armstrong, 2004). Much research has focused upon the relationship with particular reference to general practice (Cartwright, 1967; Hodson, 1967; Byrne and Long, 1976; Cartwright and Anderson, 1981; Fitton and Acheson, 1987; Butler et al., 1992; McKinstry, 1992). Furthermore, researchers have examined the effect that the doctor-patient relationship can have upon outcomes (Stewart et al., 1979) and decisions (Janis, 1984; van den Borne, 1998; Eliot and Olver, 2005; Meeker and Jezewski. 2005). Changes in the doctor-patient relationship and therefore healthcare models have also been examined (Elder and Samuel, 1987; Seedhouse and Cribb, 1989) with increased focus upon how medical professionals can best develop the necessary communication skills for their role in doctor-patient interaction (Fletcher and Freeling, 1988; Ley, 1988; Burnard, 1997; Deans, 2004, Davey et al., 2005) and similar guidelines for patients (Sharf, 1988; Gaskin, 1997). In addition to general practice, more specific contexts and aspects of doctor-patient interaction have been explored such as communication and care of terminally ill patients (May, 1995) and the extent to which the manner of doctor-patient interaction in a situation such as the delivery of a diagnosis of terminal illness can influence the patient's psychological response to their diagnosis (Dougherty et al., 1986; Barraclough, 1994; Faulker et al., 1994; Brennan, 2001; Fallowfield et al., 2002; Schofield et al., 2003).

This interest is also evident within fields of communication studies (Gwyn, 2002; sociology (Parsons, 1951; Robinson, 1973; Zola, 1972; 1973; Wright and Treacher, 1982; Williams, 1984; Waitzkin, 1989; Abbot and Pagne, 1990; Alder et al., 2004), psychology (Forshaw, 2002; Alder et al., 2004) and philosophy (Szasz, and Hollender, 1956; Widdershoven, 2007).

Further examination of the doctor-patient relationship extends to discourse and language analysis in which communication and the doctor-patient relationship are explored in relation to illness (Balint, 1986), social relations (Silverman, 1987) and patient participation (Brearely, 1990). Analysts have also considered discourse within institutional and health care contexts such as, medical interviews and counselling (Mishler, 1984; Sarangi and Roberts, 1999; Jones, 2001; Sarangi, 2002) with specific attention to notions of expertise (Sarangi, 2001; Ziebland, 2004).

Much research has been conducted in relation to doctor-patient interaction and the fact that these roles were previously considered to be fixed and forged by the traditional biomedical model in which the patient takes a more passive and compliant role in deference to the authority and expertise of the doctor. This model is often referred to as the 'paternalistic' model (McKinstry, 1992; Porter, 2004) and is rooted in the biomedical model of medicine in which the patient commonly appears as the site of illness or the carrier of health related attributes. Their role in this type of doctor-patient relationship has traditionally been confined to the presentation and reporting of symptoms, followed by adherence to the instructions of the doctor (Foucault, 1973). However, with changes in medical practice denoting modifications extending beyond the traditional biomedical model, there has been an increasing focus upon patient autonomy within medical practice and ethics (O'Neill, 1984; Bartz, 1999; Sandman, 2004; Woods, 2005; Varelius, 2006). Gradually such firmly fixed roles as inherited by the paternalistic model have made way for an increasingly flexible configuration in which the patient takes a more proactive role which has developed from unknowing and unquestioning to a more informed and inquiring patient (Janis, 1984; van den Borne, 1998; Bartz, R. 1999; Gülich, 2003; Kennedy and Lloyd-Williams, 2009a). Furthermore, the doctor is not only fallible, but has also become more accountable (Fletcher and Freeling, 1988; Donovan and Blake, 1992; Young and Flower, 2001; Calnan and Rowe, 2008).

There are several factors which have contributed to this change, some of which will be explored later within this study. One particular factor in the changing roles of

doctor and patient, considered of particular relevance to this study, has been the availability and accessibility of health information and advice from a wide range of sources. More specifically, the internet has not only made health information and advice widely available to a larger section of the population, it can be argued that the growth of websites, forums and computer-mediated consultation may have appropriated some of the medical practitioner's role. It has now become more widely accepted that the availability of medical information via the internet may have contributed to widening participation in medical knowledge and this development is regarded by some as having been instrumental in changing the role and experience of patients within modern medical practice (Klemm et al, 1998; Lemke, 1999; Collste, 2002; Lewin and Donner, 2002; Herxeimer et al, 2000; Ziebland et al, 2004).

In addition, and possibly owing to the widening participation in medical knowledge, the notion of 'expertise' has become revised to take account of all forms of expertise, including the patient's. Thus, medical expertise has become redefined as that which also includes the patient experience (Strong and Davies , 1978; Tuckett et al., 1985 ; Sarangi, 2001 ; Gülich, 2003; Shaw and Baker, 2004). This extends the parameters of expertise from the knowledge of trained professionals to the experience of patients. As a result, the patient voice has become increasingly audible within health communication and medical practitioners have recognised the importance of this voice as a source of valuable information which can inform their role and practice. In effect, this positions the patient voice as a potential resource for training medical practitioners in understanding, responding to and shaping the experience of patients.

In tandem with this, research suggests that the patient is now becoming indirectly trained in how to be this new breed of patient and this can be seen as the 'professionalisation' of the patient so that the patient may be seen to follow certain guidelines and meet certain role requirements in a manner similar to that of a trained medical practitioner (Smith and Pettegrew, 1986; Sharf, 1988; Sharf and Street, 1997; Gaskin, 1997). This development presents a new configuration of the

doctor-patient relationship whereby both parties are professionally trained experts involved in constructing the medical encounter and experience (Tuckett et al., 1985; Stewart, 2001; Stewart et al, 2003; Porter, 2004).

As mentioned previously, there has been increased focus upon the roles and language of doctor and patient within the context of medical consultations and interviews (Mishler, 1984; Sarangi and Roberts, 1999; Jones, 2001; Armstrong, 2004), patient and health information texts (Al-Sharief, 1996; Laaouina, 1998; McManus, 1999; Driscoll, 2000). There has also been significant research into patient narratives (Williams, 1984; Reissman, 1990; 2002; Radley, 1993; Greenhalgh and Hurwitz, 1999) with a more recent development which has been in the investigation of patient narratives as a source of useful data to inform principles and practice within medicine (Fletcher and Freeling, 1988; Gaskin, 1997; Viederman, 2000; Herxheimer and Ziebland, 2004).

In this respect the doctor-patient relationship is undergoing a transformation in which roles, knowledge and status are being constantly renegotiated. In lieu of the traditional model of all-knowing and authoritative doctor to uninformed and passive patient, a more fluid arrangement has developed in which doctor and patient both contribute and have an active role to play. The interaction is often characterised by information exchange in both directions and the relationship may be regarded as more of a partnership than in the past (Butler et al., 1992; Young and Flower, 2001; Chambers et al., 2003). However, whilst research has been carried out on what constitutes a good doctor, with the development of guidelines and checklists, according to Jadad et al (2006) there has been less attention to what makes a good patient.

Recent research has considered the role and features of language in the communication of patient experience. For instance, medical research has examined the role of language in pain expression (Gaston-Johannsson et al., 1990; Waddie, 1996), expressions of 'hope' (Nekolaichuk et al., 1999; Nekolaichuk and Bruera, 2004), language and discourse patterns of decision making (Jansen et al. 2001; Eliot

and Olver, 2005; Beaver and Booth, 2007) and doctor-patient information exchange patterns (Jones, 2001; Gülich, 2003). In addition to this, linguistic research has investigated specific language issues such as grammatical patterns in medical case studies whereby the grammatical choices of doctor-writers when describing patients have been found to vary considerably according to the writers' views of the roles of doctors and patients (Francis and Kramer-Dahl, 1992). Linguistic research using Functional Grammar models has examined the absence, presence and dynamism of patients in medical advice texts and found variation within grammatical choices according to text type (Laaouina, 1998) and context of health (Driscoll, 2000). In general terms, the linguistic analysis of grammatical structure can reveal how these structures are used to create meaning and how both structure and meaning converge to communicate medical experience. Despite the temptation to consider medical and patient language as somewhat distinct from each other, the current study aims to examine the 'language' as used by both medical experts and expert patients to describe medical experience and represent the experience of living with terminal cancer. A further aim is, where possible, to identify similarities as well as differences between these two sources.

In particular, the current study aims to examine the linguistic choices made by writers and speakers and how they represent patient experience of medical encounters and living with terminal illness. This is based on the view that 'language comprises a set of resources for referring to entities in the world and the ways in which those entities act on or relate to each other' (Thompson, 2004, p86). The examination of analytical findings will make it possible to compare grammatical patterns and language choices made by medical writers and real patients in the construction of these texts. In so doing, these patterns can reveal how 'transitivity grammar...construes a particular 'world view'' (Halliday, and Matthiessen, 2004, p283). A further aim is to identify similarities and differences in the world views of the speakers and writers, with particular reference to the world of terminal illness. It is hoped that the comparison of advice texts written by medical writers and interviews conducted with patients will be instrumental in exploring the

representation of patient experience of living with terminal illness, as construed from two 'expert' viewpoints.

At the most general level, the overall aim of this study is to find and focus upon the voice of the patient within the context living with terminal cancer. More specifically, the study aims to investigate how medical experience is represented in text by analysing the linguistic choices made, through which experience is communicated. It is hoped that carrying out a transitivity analysis of advice and interview texts for and with terminally ill cancer patients it may be possible to explore the representations and the reality of the patient experience in this context. Therefore, the purpose of this study is to examine the key grammatical roles and processes and how key entities, particularly patients, tend to behave grammatically in a specific set of medical texts. To this end, comparisons can be made between the two distinct data sets in order to establish whether any particular grammatical patterns arise from the data and which similarities and differences emerge from this comparison. With the advice texts indicative of the 'voice of medicine' and the patient interviews indicative of the 'voice of the life world' (Mishler, 1984), it may therefore be possible to compare assumptions and experience encoded within grammatical patterns and provide a means of measuring how closely or distantly related the assumptions about and reality of patient experience are. Given the contrasting origins of the data, it is anticipated that there may be more differences than similarities when comparing the grammatical patterns within the two sets of data.

This will involve a detailed examination of both how patients are represented grammatically in advice texts and how patients represent their own experience in the interview texts. In this way it may be possible to examine the role of the patient as evidenced by grammatical patterns and how these patterns might contribute to the identification of changes in the patient role.

Moreover, the social role of these advice and interview texts is considered to be of significance. Not only do they provide the readers of these websites with useful

information and advice about living with terminal illness, they also perform the role of construing a representation of reality regarding the experience of terminal illness. Therefore, in addition to examining the linguistic choices made in these texts, this thesis aims to explore some of the underlying assumptions about the patient's experience of terminal illness as encoded in the grammatical choices made by the producers of these texts and the experience which is constructed for the reader.

In order to do this two sets of data have been analysed. The first set comprises texts taken from a range of five different websites which specialise in providing advice for people with terminal cancer. This data was chosen because it is representative of a range of advice texts made available to patients and which are considered to be instrumental in widening patient's participation in terms of medical knowledge to become a more informed and active patient. Furthermore, the context of terminal illness is one which has more recently been added to the canon of health topics on which advice can be found on the internet.

The second set is taken from a website known as the Database of Individual Patient Experience (DIPEx), recently renamed Healthtalkonline, which contains interviews with patients with a range of health conditions. The second set of texts is taken from interviews with terminally ill cancer patients in the section related to 'living with dying'. This set of data was chosen because it is representative of the change in attitudes described above, such as notions of expertise and the expert patient. The need for such an approach to medical communication was made particularly apparent by the experiences of Ann McPherson and Andrew Herxheimer who reported specific and unanticipated difficulties in navigating the transition from their roles as professional doctors to become patients. According to McPherson and Herxheimer, this highlighted a shortfall in the provision of medical training and the extent to which it explored and accounted for the patient experience. This was felt to be particularly apparent within the context of terminal illness. In response to this, work commenced on the establishment of a database of patient narratives in which patient experience has become both an area of research and a resource for

research and advice. In short, 'DIPEx was created by Dr Ann McPherson CBE and Dr Andrew Herxheimer after their own experiences of illness. Ann had been diagnosed with breast cancer and although she knew all the medical information, couldn't find anyone else to talk to about what it was really like to have the disease.'[1].

Each text has been analysed according to the transitivity model as set out by Halliday. This model of analysis can be used to reveal how experience is represented in texts according to grammatical choices made by the writers and speakers. Following on from this, the results of the transitivity analysis have also been examined and categorised according to frequency and the emerging clustering of semantic groups. As a result, both data sets have undergone grammatical, quantitative and qualitative analysis.

The following chapter will provide an overview of the theories and principles which form the background for this study. Firstly, it will consider the necessary theoretical background to the linguistic and analytical approach and principles on which this study is based. This will involve a summary of the key principles of functional grammar and an overview of the relationship between grammar and meaning as set out by Halliday (1978, 1985a). In addition, the linguistic concept of dynamism (Hassan, 1985/1989) will also be outlined in order to consider how the impact of actions carried out by patients can be measured. Secondly, an overview of health models and health communication research will be presented, specifically in relation to the context of terminal illness. This will provide contextual background on related models of health from which the palliative model has emerged and with which it coexists. It will briefly outline the areas in which the palliative model differs from other health models but also indicate certain similarities. This will lead on to an overview of related aspects of health communication research within the context of terminal illness.

Following on from this, chapter three will describe in detail the methodology and analytical tools as applied to the data and overview the data in context. Firstly, the

aims of the study will be reiterated and positioned clearly within the context of the current data, involving a detailed description of the background to and rationale behind the choice of data. This will involve a detailed overview of the transitivity system in which the six key types and related sub-types of grammatical processes will be explained. In tandem with the process types, the corresponding grammatical participants will be presented with key examples from the advice and interview data to demonstrate these analytical categories. Certain complexities of the transitivity system will also be examined and chapter three will extend the focus of the previous chapter in relation to the analysis of dynamism within transitivity. In addition to the identification of complexities within the transitivity system, further methodological considerations will be outlined such as the context and comparability of the two data sets and certain practicalities of analytical process such as blends and overlaps between process types.

The analytical findings will then be presented and discussed in relation to each data set in order to consider key findings which address the research aims of this study. Chapters four and five will relate to the advice and interview data respectively and each chapter will follow a similar structure. This will provide an overview of the patient in terms of their participation in grammatical roles within the transitivity system. These will be presented overall according to dynamic value and then considered in more detail according to the frequency with which they occur. Those roles which are occupied with greater frequency will be examined and discussed in relation to how experience is represented by the grammatical patterns which emerge from the data. These patterns will also be discussed with reference to health communication research, communication theories and palliative care models.

Finally, the closing chapter will summarise the conclusions of the thesis in relation to the original research questions. This will consider the overall findings within and across the two data sets and attempt to establish the key similarities and differences therein. It will also return to the original hypothesis of the likelihood of

differences being greater than similarities when comparing grammatical patterns in the advice and interview texts in the current study. Finally, the possible contribution of the study will be examined, including its limitations and any specific recommendations for applications to health communication or further research which can be made based upon the findings of the current study.

Chapter Two: Theoretical Background

A number of theoretical aspects merit attention in order to both place the current study within an appropriate framework and outline the underlying principles which underpin and inform the study. Therefore this chapter aims to identify and describe certain key contexts, concepts and approaches. These concepts can be divided into two key areas of particular relevance to the current study which are Functional Grammar and the transitivity system, along with health communication research within the context of terminal illness. This requires an in depth presentation of the relevant linguistic background and in particular the theoretical principles upon which this study is based. In addition, the health communication setting of palliative medicine will be outlined and include a concise diachronic overview of the developments within medical models which place the palliative model in context. However, greater attention will be afforded to the palliative model, its relationship with other models and health communication within this context. This will also require some attention to the changing roles of participants within medicine, in particular the patient, developments in health communication and a survey of the role of language within these particular areas.

2.1 Functional Grammar

A functional approach to language takes meaning and function as the basis for grammatical structure so that rather than meaning being a consequence of grammatical patterns, these patterns are determined by the meanings of the user and the function for which language is being used (Halliday, 1978). This approach to language is based upon the premise that the fundamental role of language is to realise meanings and achieve particular functions (Thompson, 2004). With this in mind, a central concern within Functional Grammar is the exploration of how meanings and functions are achieved and structured within language.

Halliday's framework (1985a) presents three core types of meaning and function within language use and examines the ways in which language is structured in order to achieve both. These are the experiential, interpersonal and textual functions of language which serve to describe experience, interact with others and organise information. Each metafunction is both structured and realised by the 'wordings' chosen by the user, selected from a range of possible wordings and it is the chosen wording of the user which makes the realisation of meaning and function possible (Thompson, 2004). The first of the three metafunctions, relating to how language is used to describe experience and talk about the world, will be the primary focus of the linguistic analysis within this study and will be used to examine the lexico-grammatical choices made to describe patients' experience of living with terminal illness.

Inherent in this approach is the concept of choices made by language users and the way in which these choices shape meanings. The basic assumption is that wordings and structures are chosen from a set of possible options; therefore the wording might otherwise have been chosen differently and the meaning realised differently (Halliday, 1985a).

However, it should be highlighted that the choices made by language users are influenced by context as well as function and that certain choices might more typically be made within certain contexts, depending upon conventions and appropriacy. The influence of context upon language choices will be considered further in the following chapter in which the analytical approach and Transitivity System will be described in detail.

Finally, the application of linguistic theories has been used to reveal patterns within, and the development of, professional discourse (Bazerman, 1988; Bhatia, 1993; Scollon and Scollon, 1995; Sarangi and van Leeuwen, 2003). Similarly, the linguistic analysis of patient language can be used to examine the development of professional patient discourse. In comparison to other types of patient, it should be emphasised that the context of terminal illness presents a unique frame of

reference which requires a different way of looking at the world and being in the world (Tamura et al., 2006). In order to examine the terminally ill patient's experience of being in the world, patient language can reveal much about their representation of the experience of living with dying. One particular theoretical and analytical approach of relevance to the current study is that of dynamism, which will be summarised below.

2.1.1 Dynamism

The notion of dynamism is concerned with whether and to what extent any action or process impacts upon something or someone. In simple terms, dynamism relates to who does what to who and how the actions of one person or entity may affect another. Broadly speaking, actions which impact upon another entity can be deemed as more dynamic than those which do not. With this in mind it is possible to say that some participation and therefore some participants can be more active and dynamic than others (Halliday, 1981).

Dynamism is of significance to the current study in that it makes it possible to measure and indicate how much the people involved within the medical situation have an impact within the actions they participate in. To be more precise it can help to show how effectual a doctor, patient or family member appears within the wider medical context and specific medical processes they participate in. It can also help to reveal how an entity such as the illness itself impacts upon other entities. By measuring dynamism in this way it may be possible to compare the key entities involved in the medical context in terms of their overall impact and efficacy.

Furthermore, this can enable an examination of the 'ideal' roles construed in medical discourse for different entities such as doctors, patients and family members. By comparing these representations within different types of medical discourse as generated by patients and doctors, it may also be possible to consider the similarities and differences between the representations and ideals presented by both perspectives.

The first attempt to measure dynamism in this way was put forward by Hasan (1985/1989) whereby a cline of dynamism was constructed with participant roles ranging from active at one end of the scale to passive at the other. This original cline has been adapted below to include examples taken from the current data to demonstrate each main participant role within a context. It should also be mentioned that these participant roles will be explained in greater detail within the methodology section. At present, the focus is merely upon the examples of participant roles in context and how they fit within a general scale of dynamic value. This scale will also be returned to when considering how it can be applied to the current study.

Dynamic

↑	1 Actor + animate goal	I will...push them (the doctors).
	2 Actor + inanimate goal	I write down a list of questions and points
	3 Sayer + recipient	Well I haven't asked them specifically how many years...
	4 Sayer + target	...I can voice my feelings...
	5 Sayer	...when I say it doesn't bother me...
	6 Phenomenon + senser	I (don't want to) upset anybody.
	7 Senser	I don't know (regarding euthanasia)...
	8 Actor – goal Senser + phenomenon	...to make sure I didn't overdose... Somebody (this mentor) who knows about all the contacts...
	9 Behaver	...I woke up in the Intensive Care Unit.
	10 Carrier	both my wife and I had up to date wills in place.
	11 Goal/target	... somebody wanting to get rid of their relatives...
	12 Range	... when you're seeing a consultant...
↓	13 Circumstance	... they put the needle in me...

Passive

Fig. 1 Cline of Dynamism *Based upon Hasan 1985/1989*

The scale shows how, according to Hasan, the Actor 'I' at level one who acts upon another person 'the doctors' possesses greater dynamism than an Actor who acts upon an inanimate or non-human Goal at level two. However, both these Actors are considered more dynamic than the later example at level 8 because their activity is directed towards another entity. This can be contrasted with level 8's

Actor without a Goal, whose activity is not directed at another entity, at the less dynamic level eight.

The following three levels of dynamism involve the role of Sayer. In common with the role of Actor, more than one type of Sayer may be involved with varying degrees of dynamism. This depends upon whether the Sayer is speaking to somebody (level three), about somebody or something (level four) or merely saying something (level five). Verbal participation is deemed more dynamic than some other types of participation as it requires external activity.

Levels six to eight are occupied by participants involved in mental processes. Level six involves a Phenomenon acting upon a Senser. This appears two levels above the reverse, and indeed more usual, configuration of the Senser acting in response to a Phenomenon at level eight. Between these two levels a solitary Senser appears with no Phenomenon at level seven. This Senser 'I' participates in the activity of 'not knowing' but this activity does not extend to a particular Phenomenon. Again, it is the notion of a participant acting upon another or having an effect upon another which leads to the greater degree of dynamism as can be seen in the two examples below.

It is also worth mentioning that Hasan's original cline of dynamism did not contain the more usual configuration of a Senser acting in response to a Phenomenon in a mental process, as found in the first example above and at level eight. This has therefore been added to include the more common wording which is, broadly speaking, equivalent in dynamic terms to an Actor without a Goal, whose activity is not directed at another entity. Therefore both these participants appear at level eight.

Somebody (this mentor) who knows about all the **contacts**...			*(unmarked, less dynamic)*
Senser	Mental process	**Phenomenon**	

I (don't want to) upset		**anybody**.	*(marked, more dynamic)*
Phenomenon	Mental process	**Senser**	

Based on the same rationale that their activity is not directed at another entity both Behaver and Carrier appear further down the scale at levels nine and ten respectively. Whilst Behaver is involved in activity (or behaviour), the role of Carrier is related to states rather than activity and therefore appears in a less dynamic position on the scale than Behaver.

At the next level the role of Goal can be said to possess no dynamism as it is being acted upon by an Actor. Similarly Range, at level twelve, is devoid of dynamism as it is a part of the main Actor's activity and not involved in any independent activity. Finally, Circumstance is in the least dynamism position at level thirteen as its function is to supply the context or background to other roles and their activities rather than participating directly in any activity of its own.

The cline above and these examples show briefly how dynamism can be used to consider who does what to who and how the actions of one entity may or may not affect another. More specifically, it can be used as a means of measuring the extent to which those who participate in the medical situation and processes have an impact or effect upon other entities. Furthermore, based upon further revisions by Thompson (2006), the above table can be broadly divided into regions of high, medium and low dynamism as follows, ranging from level one at the highest to level thirteen at the lowest.

Cline of Dynamism

Participant Role	DYNAMISM
↑ 1 Actor + animate goal	HIGH
2 Actor + inanimate goal	
3 Sayer + recipient	MEDIUM
4 Sayer + target	
5 Sayer	
6 Phenomenon + senser	
7 Senser	
8 Actor – goal Senser + phenomenon	
9 Behaver	LOW
10 Carrier	
11 Goal/target	ZERO
12 Range	
↓ 13 Circumstance	

Fig. 2 Cline of Dynamism in Bands

However, this division is not as straightforward as these simple labels seem to suggest. This is partly due to the fact that the original arrangement of the cline itself is neither comprehensive nor clear-cut. In addition to the categories which emerged from Hasan's original data, others have emerged when the cline of dynamism has been applied by other analysts to different data. In certain cases, and for reasons which will be discussed in more detail later, roles have been repositioned within the scale. Nevertheless, this version reveals the first attempt to consider participant roles in this particularly systematic way in terms of their dynamism. As such it is the foundation scale of dynamism upon which later revisions have been based. Some of these main revisions will be outlined in more detail in the following chapter. Similarly, the overlay of wider bands upon the cline such as high, low and medium dynamism will be returned to later in the methodology section.

In spite of there being slightly different versions of the cline of dynamism, the essential aim of it as an analytical tool to reveal how the actions of one entity affect another remains unchanged. This aim is of importance to the current study because as speakers or writers we choose to encode our experience of the world in a

particular way. Analysing patient interviews and medical advice in terms of transitivity choices and dynamism can provide insights into the medical context of terminal illness from the viewpoints of both patients and doctors. Firstly, an analysis of patient interviews can provide an overview of how the medical experience of some patients is represented by themselves. It can bring to light how they experience their medical situation, processes and how they affect or are affected by other entities involved. Secondly, the experience of terminal illness as represented by the medical establishment can be examined by analysing medical advice texts. Given the range of grammatical choices it is possible that these two voices will represent the same event differently in terms of participant roles and therefore also dynamism which is directly relevant to a further aim of this study to compare these different representations by patients and doctors. This will be returned to and expanded upon in the following chapter using examples from the current data to demonstrate varying representations of and shifting dynamism within the 'same' event.

2.2 Background to the Palliative Model of Medicine

In order to outline the palliative model of medicine it may be useful to briefly consider the context in which the model arose and previous models from which it drew and was influenced by.

2.2.1 The Biomedical Model

The biomedical model can generally be considered as the dominant model within modern medicine. A degree of criticism has been levelled at this model, some of which will be explored later in this section and alternative models have developed. However, it should be noted that the biomedical model remains as a central approach to healthcare. In addition, it is a modal which has influenced developments in the palliative model, as will be explored later in this chapter when examining the relationship between different models of health. In essence, the biomedical model views people as 'biological machines' (Banyard, 1996, p4) where if something fails to function correctly, it can be repaired or replaced. As a model of health its appeal lies in the fact that the human body is comprised of various biological components which in theory can be treated individually and successfully. According to Banyard's overview there are four key features of this model which are outlined briefly below.

In the first instance it can be described as reductionist in that it attempts 'to reduce explanations of illness to the simplest possible process' (Banyard, 1996, p4) by focusing upon individual parts of the body rather than the person as a whole. A further characteristic of the model is that of 'single-factor causes' whereby one main cause of an illness is considered rather than a combination of possible causes. The third feature of the biomedical model is its dependence upon the 'mind-body distinction'. This is based on philosophical and religious concepts which regard the spirit and machine as two distinct components of the person. Finally, it is characterised by its focus upon illness rather than health and in so doing tends to overlook areas such as illness prevention and health promotion (Banyard, 1996).

However, the biomedical model has come to be regarded by some as an inadequate or even unsuitable model in certain medical contexts owing to a number of key considerations which can be summarised briefly. Firstly, there is now generally a lower incidence of single cause infectious diseases such as Tuberculosis but a higher incidence of multiple cause chronic diseases such as heart disease. Furthermore, technological advances have led to higher financial requirements for many treatments which in turn has resulted in a greater demand for illness prevention and health promotion. Thirdly, there is now greater focus upon 'quality of life' and our expectations of a healthy lifestyle which have become part of that (Banyard, 1996). Given these developments within healthcare it could be argued that there is a degree of incompatibility between certain healthcare trends and needs.

As a model which, as the name implies, is concerned with biology and medicine, it has been shown to have some limits in terms of both. It has also been argued by some that the inadequacies of the biomedical model go beyond purely biological and medical realms. In discussing the sociology of medicine, Armstrong (1994, p1) also highlights the limitations of biomedicine in being able to adequately account for or explain all processes sufficiently insofar as '...there seem to be aspects of human functioning which fall outside the classical biomedical model.' Furthermore, it has been argued that the dominance of the model has contributed to 'a narrowing of medical vision' (Helman, 2001, p65) and has been counterproductive in terms of the development of expert knowledge of illness as it has led to the exclusion of '...alternative explanations and understandings of the nature of illness (Armstrong, 1994, p2).' Furthermore, the biomedical model appears to have overlooked lay perceptions and explanations of illness and how these may influence patient behaviour. Therefore, the need to carry out further systematic research in these areas has been identified (Calnan, 1987). In brief, the biomedical model 'became increasingly outmoded as we began to generate more and more questions which it could not provide answers for' (Forshaw, 2002, p5).

Notably, criticisms of the biomedical model have not been limited to 'outside' sources such as philosophy, sociology, psychology, historians and so on but have

swelled to include dissatisfaction from within the field of medicine itself. For example, the fact that the biomedical model is rooted within the concept of Cartesian dualism has become a widely held point of contention across multiple disciplines (Foucault, 1973; Armstrong, 1982, 1983; Balint, 1986; Silverman, 1987; Greenhalgh and Hurwitz; 1999, Helman, 2001). More specifically, medical practitioners have pointed out that non-biological issues may be more central to the concerns of medicine than previously realised or accounted for and this point is of direct relevance when considering the development of the palliative model which will be considered in more detail within this chapter.

> At its most arid, modern medicine lacks a metric for existential qualities such as the inner hurt, despair, hope, grief, and moral pain that frequently accompany, and often indeed constitute, the illnesses from which people suffer (Greenhalgh and Hurwitz, 1999, p 50).

These factors and limitations have contributed towards changing both lay and professional perceptions of health as well as the medical models they are framed within. As these changes have taken place, alternative models have gradually been suggested and developed.

2.2.2 The Biopsychosocial Model

The biopsychosocial model (Engel, 1977) emerged largely as a reaction to the biomedical model. As the name suggests, this model considers the influence of all three factors upon health and illness. It differs from the biomedical model in that it takes a more complex view of health and illness processes. It regards cause and effect as a combination of factors rather than taking a single issue approach. In addition, it considers causes on a number of levels. Between the two polarities of ecological and physical systems, the biopsychosocial model concerns itself with the three core and interconnected levels of biological, psychological and social systems. It therefore takes as one of its central premises the interaction between human functions and systems ranging from cellular to cognitive to cultural.

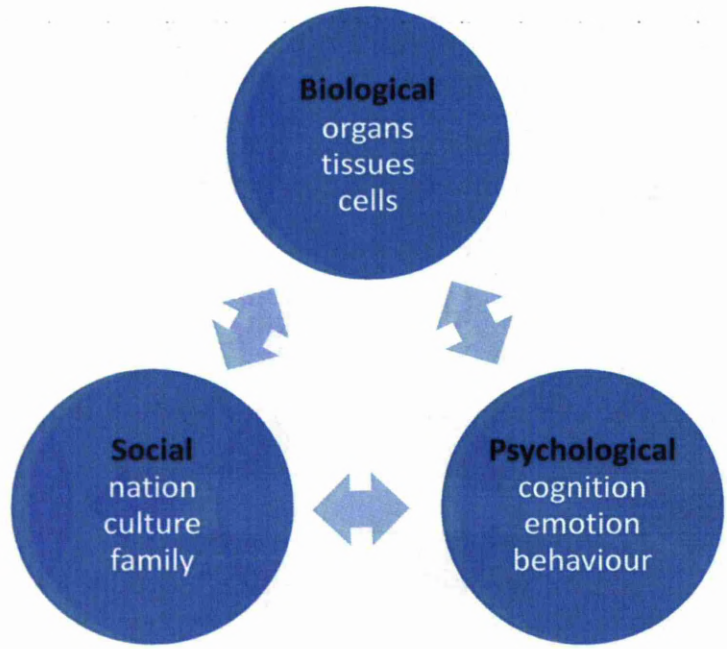


Fig. 3 The Biopsychosocial Model (adapted from Banyard, 1996, p6)

Unlike the biomedical model, the biopsychosocial model does not distinguish between mind and body but rather '...looks at the connections between mental events and biological changes' (Banyard, 1996, p5). Finally, this model does not restrict its focus to illness only but is equally interested in health. As an approach to health and illness it takes a multi-disciplinary route to the complex analysis and management of medical cause, effect and solution (Stuckly, 2004). In relation to the current study, it is of some interest that the three key areas identified within the psychological sphere overlap to some extent with mental and behavioural process types within the transitivity system.

Both the biomedical and biopsychosocial models can be regarded as fundamental to all medical models, whether they are extensions of or reactions to these two key models in recent medical history and practice. These earlier models provide a context for and have a bearing upon the development of alternative models of health which have emerged in more recent times. One such recent model, the palliative model is central to the current study and will be examined in more detail in the following section.

Whilst previous medical models are of general significance, it must be stated that they are not necessarily equally well suited for all health contexts. Given that the context of health in the current study is terminal illness, there are several aspects of the more general health and relationship models which tend to be at worst irrelevant or at best require adaptation. This is largely because the primary goal of medicine is to cure and most medical models work from the assumption that a medical problem can be solved. This definition means that modern medicine has generally given priority to curable illnesses (Clark, 1999).

Whilst both the assumption and the goal are generally understandable and admirable, there is a sense in which they are deemed somewhat inappropriate where the problem cannot be solved because the illness cannot be cured. It is in this situation that, until recently, traditional modern medicine had made very little provision. Part of the reason for this lay in the fact that, until very recently, terminal illness seemed to present an insurmountable challenge to medicine which on a certain level defied the goals of modern medicine at that time.

> In the middle part of the 20th century death was seen as a medical failure. Spectacular medical and social advances had robbed formerly killer diseases of their potency...When treatments failed to arrest the progress of diseases, health practitioners found they did not have the wherewithal to manage a patient's death (Mitchell, 2008, pp1-2).

The fact remained that on the whole modern medicine had prioritised curable illnesses and therefore curable patients at the expense of those who cannot be cured (Armstrong-Coster, 2004). 'Health care professionals trained in a culture of "cure," seemed unable to respond to the needs of the dying patient and their families' (Ellershaw, 2002, p617). It was this shortfall within medical training, practice and experience which led to the foundation of the palliative care model in Britain in the latter part of the 20th century.

2.3 The Palliative Model

In the past care of the dying had typically been the responsibility of family members. However, this situation was becoming less feasible and therefore satisfactory in post war Britain (Leak, 1948). Palliative care grew out of the recognition that the remit of modern medicine needed to be broadened to include the care of people up to and including the moment of death. However, prior to the hospice movement, it could be argued that most terminally ill patients' experience of medical care was characterised by a gradual reduction in or possibly even absence of care. In Leak's assessment 'treatment can almost be written in one word – morphine' (1948, p85). Consequently, it was not unusual that the experience of a terminally ill or dying patient often involved a degree of abandonment, isolation and exile as a result of the medicalisation of dying (Gorer, 1965; Illich, 1976; Ariès, 1976, 1981; Elias, 1985; Armstrong-Coster, 2004 and Mitchel, 2008).

Although the twentieth century saw widespread improvements in health care and policy Clark (1999) argues that despite the post-war establishment of the National Health Service and its claim to provide care 'from the cradle to the grave', it was some time before efforts to address the latter point of that particular arc were embarked upon.

> In the first two decades of its existence there is little evidence that the NHS offered any strategic or operational guidance on the care of the dying. Indeed, where such guidance did appear, it was usually from charitable and philanthropic sources (Clark, 1999, p225).

As Clark (1999) points out, it was not until the endeavours of such 'philanthropic sources' gained the support of some of the first cohort of NHS trained doctors, that changes in thinking, approach and finally policy gained interest and momentum.

Two key proponents of this shift were Kübler-Ross (1973, 1981, 1997), Saunders (1958, 1977), Saunders et al., (1981) and Saunders and Baines (1983) whose work aimed to address the needs of terminally ill patients. Saunders was instrumental in

the establishment of the first hospice in London in 1967 which was set up as an alternative to the traditional hospital setting with its focus upon cure and discharge. St Christopher's Hospice was founded specifically in order to provide a place from which patients could approach death with the support they required. It is also worth highlighting that this support was not restricted to exclusively medical support. 'In the hospice movement we continue to be concerned both with the sophisticated science of our treatments and with the art of our caring, bringing competence alongside compassion' (Saunders et al., 1981, p4). Thus matters such as the role of the family, cultural considerations and emotional reactions began to be considered alongside issues of symptom and pain management.

Meanwhile Kübler-Ross' work in America (1973), whilst acknowledging commonly held beliefs, attempted to revise notions of death and proposed a more positive approach to the experience of dying. Her work with terminally ill patients led to the identification of five key stages in the overall process; namely denial and isolation, anger, bargaining, depression and acceptance. The aim of this work was essentially 'to sensitize family members of terminally ill patients and hospital personnel to the implicit communications of dying patients' (p129). These theories were also accompanied by a move away from previously held specific religious beliefs connected to death towards more general spirituality in the context of dying.

There has been some criticism of Kübler-Ross' model, notably for its tendency towards individualism over society (Mellor, 1993) and the inherent risk of compounding feelings of disillusionment if a positive approach to death cannot be realised (Lofland, 1978). However, it has also and mostly been held up as an example which has been partly responsible for bringing the experience of dying into the open (Walter, 1991, 1994) and thereby making it less of a closed subject and isolating experience. Overall the model remains valued and regarded as relevant within its field (Walter, 1991, 1994; Field, 1996; Armstrong-Coster, 2004). It is also regarded as having been instrumental in the evaluation of our relationship with death and dying. As Mitchell (2008, p2) points out, Kübler-Ross' writings 'forced

society to look at how it understood death, and how it should understand the experience of, and relate to, the dying.'

The eventual emergence of the hospice movement can be regarded as timely given that developments in medicine, palliative and otherwise, have resulted in 'more individuals living in the midst of prolonged dying trajectories than ever before' (Armstrong-Coster, 2004, p9). In this respect it may be fair to say palliative care is now meeting a medical demand which, although it had previously existed, had not done so on the current scale. In effect it was the innovative work of Saunders and Kübler-Ross which anticipated the scale and began taking steps to deal with the demands.

In so doing they helped to bring about the wider recognition of the fact that dying patients are not without needs, those needs are highly specific and go beyond the realms of purely medical needs. It is also worth emphasising that the demands in terms of medical care cannot be addressed without also considering the requirements of medical training in this field. Therefore, their work has led directly to considerable changes in medical training as well as practice to ensure that the remit of medicine has broadened to include the care of people up to and including the moment of death. Their work may also be regarded as a contributory factor in changing lay perceptions, expectations and experiences of death and have provided some underpinning for the more recently emerging concept of a 'good' death (Armstrong-Coster, 2004) - a concept which will be explored further in the relevant section.

It may be partly the case that it took some time for medicine to begin implementing the findings and approaches of Saunders and Kübler-Ross. Interestingly, it was not until 1987 that palliative medicine was fully recognised by the Royal College of Physicians as a medical speciality (Charlton, 2002) and it is only relatively recently that palliative care has become more fully explored as an explicit part of medical research, training and expertise (Ellershaw and Ward, 2003). Despite the fact that progress has been made, the general consensus appears to be

that there is much which remains to be done (Armstrong-Coster, 2004; Grand, 2009). In considering the current need for palliative care Koffman et al. assert that we should not underestimate the scale of the problem and the scope for improvement.

> While we have witnessed a growing understanding of the palliative care needs of patients and their families and an acceptance that death is universal – which, *de facto*, makes it a universal public health concern – the actual provision of care has remained in part woefully inadequate (2008, p7).

In order to consider how this particular medical model frames the medical experience it is necessary to provide a more precise definition of palliative care and its parameters. At its most general, palliative care 'is the support provided for people who are terminally ill' (Forshaw, 2002, p147) within which the objective 'is no longer cure but the chance of living to his fullest potential in physical ease and activity with the assurance of personal relationships until he dies' (Saunders, 1983, p vi). The definition can also be expanded to include concerns beyond those of the individual patient.

> The palliative 'total care' model aims to offer high-quality care not just to the patients but also to their families and informal carers, who may be relatives, partners, friends and members of their wider community. The tasks they perform may be broad including one or more of practical, emotional and physical care (Koffman et al., 2008, p17).

> It is the care of patients with advanced and progressive disease for whom the focus of care is quality of life and in whom the prognosis is limited, but may be a number of years. It includes consideration of the family's needs before and after the patient's death, as well as bereavement and the care of patients who are dying due to cancer and diseases other than cancer (Charlton, 2002, ppvii-viii).

A further distinction which Charlton (2002) highlights is between palliative medicine and palliative care.

> Palliative medicine infers a discipline that is practised by specialists, whereas palliative care is the care provided by a multidisciplinary team of doctors, nurses, therapists, social workers, clergy and volunteers. Thus this care involves much more than the science of symptom control (pvii).

The latter has become increasingly important and whereas in the past the two may have been thought of and practised more separately, they have now become entwined in the experience of the patient with a terminal illness. Therefore this study is interested in both aspects of palliation as part of the whole patient experience although the distinction between the medicine and care may be of relevance when considering different roles and the relevant people and agencies involved in medicine and care.

It is evident that significant progress has been made in the field of palliative care. However, further developments have been suggested. Saunders (1981, cited in Torrens) favours ongoing evaluation of medical beliefs and practice. In the views of both Torrens and Saunders (1981) if palliative care, or any type of care for that matter, is to continue to be effective, it cannot afford to be complacent or ever assert that the model is complete. It never can be complete owing to the fact that it is constantly evolving.

There are certain aspects of the palliative model which have been identified as requiring further research and development (Grand, 2009). For example, whilst there have been significant advances in some clinical aspects of cancer care, there is still room for improvement when it comes to areas such as doctor-patient communication (Michiels et al., 2009; Ache and Wallace, 2009) and decision-making processes (Pugh et al., 2009). Perhaps most importantly for this study it is felt that there needs to be increased attention to the patient experience (Armstrong-Coster, 2004). This can be seen within the wider context as part of a general trend in medicine to pay greater attention to this aspect of medical experience.

To focus upon the experience of the patient can be regarded as important both for its own sake and to provide a valid source of information (Greenhalgh and Hurwitz,

1999; Pope et al., 2000; Pope and Mays, 2000; Grumann and Spiegel, 2003; Kellehear, 2009). Armstrong-Coster (2004) highlights the understandable taboos and silence surrounding death-related issues which have left us with '...a dearth of valid, truthful experiential accounts of dying which warrants immediate attention' (2004, p ix). Her work with individual patient narratives is an attempt to address the crucial knowledge and skills gap which has arisen from such silence. Furthermore, the patient experience and a more patient oriented focus has not been limited to social sciences but has also become increasingly central to clinical methods within palliative care as outlined in the following section.

To summarise, as mentioned previously, both the biomedical and biopsychosocial models can be regarded as fundamental to all medical models. In some respects the biopsychosocial model can be regarded as superseding the basic biomedical model and it may be fair to say that it also shares several features with it. However, it should also be highlighted that the biomedical model has not become redundant but rather that it has been expanded upon to include other factors in the medical processes of cause, effect and solution. In general, both models share a focus upon curative medicine where the process is usually one of diagnosis, treatment and cure.

The palliative model also shares some features of both the previous models. Whilst the ultimate goal may differ, it has been argued that all three models share similar core values. 'Palliative care shares the same values as standard curative care: looking after people, supporting them, and providing the best possible quality of life until life is over' (Foreshaw, 2002, p147). However, the palliative model has expanded health care in an entirely different direction, away from curative medicine towards end-of-life care and death. The relationship between the biomedical, biopsychosocial and palliative models can be summarised diagrammatically to show that there is some overlap between all three. In brief it could be argued that the palliative model is redressing a certain balance by providing for an area of health care which neither of the previous two models was designed for.

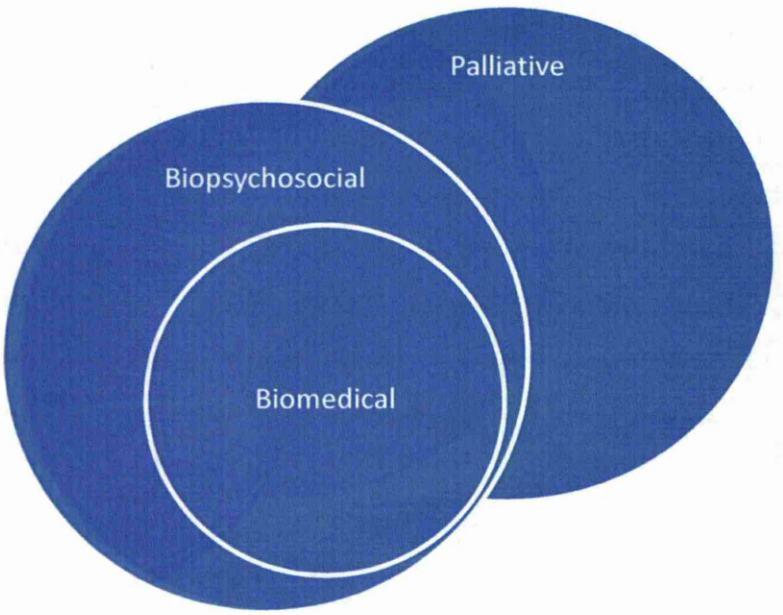


Fig. 4 The Relationship between the Biomedical, Biopsychosocial and Palliative models.

Where previous models focused more upon the illness and a curative approach to medicine, the palliative model's priorities differ somewhat. This is not to say that the palliative model bears no relation to previous models. For example, it would not be accurate to say that the illness is overlooked; it is in fact fundamental to the palliative context of health. Furthermore, although a purely curative approach may not be entirely appropriate, certain aspects of symptom alleviation and pain management in palliative care are not unrelated to a curative biomedical approach. So whilst connections exist across all three models, there is some variation in terms of priorities and approach.

A clear illustration of both overlap and variation is the case of a 'patient-centred' approach. As mentioned previously, the biopsychosocial (Engel, 1977) model takes account of the interaction between human functions and systems ranging from biological to psychological and social spheres. In this respect it can be seen as far more patient-focused than illness-focused and contrasts with the biomedical model because it includes psychological and social factors relevant to the patient in their

real world context rather than simply treating them as a psychologically and socially disconnected site of illness.

The palliative model has taken this patient-centred theory and approach further still in applying it to construct a clinical method in which illness is investigated both in itself, as well as within the wider context of 'the patient's experience of being ill with the disease' (Mitchell, 2008, p3). This then leads on to an examination of the disease within the context of the whole person, considering issues such as ideas and emotions in addition to symptoms. Within this approach the doctor-patient relationship is regarded as a key component and so the roles and relationship between these two parties requires further examination.

2.4 Medical Models and Relationships

As models of health, the biomedical and biopsychosocial models have also influenced the changing role of medicine in society and particularly the roles of and relationship between doctor and patient (Armstrong, 1982, 1983, 1995). In many respects it is difficult to separate models of health from roles and relationships. For example, the biomedical model defines the patient as a collection of body parts wherein certain problematic parts provide a subject of medical observation and treatment (Foucault, 1973; Forshaw, 2002). The ways in which medical models provide a framework for and influence relationships between those involved in medical encounters can and should be analysed in greater detail.

As mentioned previously, the limitations of earlier and more generalised models have made it necessary to revise and update medical models and this in turn has both absorbed and contributed to changes in lay and professional health perceptions. A further consideration which has brought about considerable change lies in the fact that there has been increased attention to the nature of relationships between health participants; namely patients and health practitioners. At the same time as this aspect of medical experience has come to be regarded as increasingly significant, it has become evident that a model such as the biomedical model may have certain limitations in terms of the promotion and development of doctor-patient relationships (Foucault, 1973; Balint, 1986; Taylor, 2003). Therefore it could be argued that certain developments in medical models and relationships are intertwined and have taken place in tandem with each other. The interdependent nature of both medical models and relationships can perhaps be best exemplified by advances made in the development of the palliative care model. However, before examining this claim in more detail, it is first necessary to outline some of the broader and more general frameworks within which the doctor-patient relationship exists.

2.4.1 The Doctor – Patient Relationship

The doctor-patient relationship can function and be characterised in a number of different ways. Four key models have been identified (Porter, 2004) and can be summarised briefly below.

Model	Features
Paternalistic	Doctor as expert – patient as passive and compliant
Mutual	Doctor and patient as expert – patient as autonomous
Consumerist	Doctor as service provider – patient as client
Default	Low engagement between doctor and patient

Fig. 5 An overview of Doctor-Patient relationship models

The first of these can be regarded as more typical of the biomedical model although it also extends the parameters beyond the scope of biological illness alone and provides a framework within which the doctor-patient relationship is of significance. Within a paternalistic framework, the doctor performs the role of authoritative expert, whilst the patient adopts 'the sick role' (Parsons, 1951) in an arrangement which can be regarded as akin to a parent-child relationship. In contrast, the mutual and consumerist approaches to health care are now becoming more common. It has also been argued that the mutual model has developed as a result of patient's possessing greater knowledge of medical matters and this has been found to be particularly true within the context of chronic illness (Porter, 2004).

A further context in which a more autonomous patient is becoming apparent is within the context of terminal illness. There has been research into various aspects of terminal illness and living with dying such as Glaser and Strauss' (1965) research into communication patterns between health practitioners, dying patients and their family members. In particular the significance of patient knowledge and control has been emphasised and the effect of both upon patient awareness. Glaser and Strauss' research with terminally ill patients led to the identification of four types of

awareness context and considered the effect that each might have upon doctor-patient interaction (1965). These can be summarised and regarded as a progressive route of awareness although the awareness experience of the terminally ill patient may not always follow such a strictly linear path.

Context	Features
Closed awareness	no knowledge of dying
Suspicion awareness	suspicion of dying
Mutual awareness	mutual pretence/deception of dying
Open awareness	open awareness and acceptance of dying

Fig.6 An overview of awareness of dying contexts (Glaser and Strauss, 1965)

2.5 Health Communication in Palliative Care

A key development in the doctor-patient relationship has been the development of health communication for patients in which medical knowledge is no longer considered exclusive to medical professionals. The recognition of patients' own knowledge with regard to their terminal illness has enabled the doctor-patient relationship to progress from the paternalistic model of interaction to one of increasingly mutual exchange.

In addition to patients' increased knowledge of their own illness and its terminal nature, there has been wider access to medical information via patient information leaflets and websites. The presence of and access to such health information can be seen as indicative of general developments in the channelling of medical information towards patients. However, the mere existence of more widely available information relating specifically to terminal illness is a relatively recent development and one which represents a new direction within health communication becoming more commonplace.

It may also be fair to say that with the availability of online information, there have been more rapid advances within a shorter and more recent timescale. Consequently, this has led to the somewhat sudden arrival of a more informed and knowing patient, in which internet use has become a more integral part of the terminally ill patient's experience (Ziebland, 2004; Ziebland et al., 2004). This has been found to influence medical roles, relationships and interaction in a number of ways. For example, access to online medical information for patients (Mooney and Sarangi, 2003), the establishment of internet doctors (Collste, 2002), the development of online patient support groups (Klemm et al., 1998) and the use of the internet as a forum for shared patient experience (Herxheimer et al., 2000). Moreover, the potential influence of the internet extends to areas such as directly influencing patient experience of terminal illness (Ziebland et al., 2004) and the use of patient experience as a resource for both understanding patients (Vanderford et al, 1997) and training professionals (Herxheimer and Ziebland, 2004).

The role of language has not been insignificant in contributing to this. Historically, language has taken a central role in the development of medical science and practice and continues to do so with the arrival of the internet and its function of gathering and disseminating information. The internet has provided a forum through which medical information can be circulated amongst vast numbers of people at any given moment and has led to an increase in the pace at which this information can be circulated so that it can go from being highly specialist knowledge to almost general knowledge in a very short space of time. The tool through which this process originates and is being conducted is through language and thus this study is essentially concerned with how language is being used on the internet to communicate with patients. It is concerned not only with the features of that language, but also the role of language in informing experience. The following section will outline the central approach to language taken in this study and some of the key principles which will be developed further within the methodology chapter.

Chapter Three: Methods and Materials

3.1 Aims

Having considered some of the previous research which is relevant to and underpins this study, it is now necessary to reiterate the aims of the current research. In very general terms, the overall aim from the outset has been to find and focus upon the voice of the patient within the context of medical experience.

This carries on from previous research (Driscoll, 2000) whereby patient advice was analysed in an attempt to uncover assumptions about the role of the 'ideal' patient and how she or he is represented as being, thinking, feeling and behaving. However it was felt that such research could be taken further by exploring the reality of patient experience in comparison with assumptions, as a means of measuring how closely or distantly related the assumptions about and reality of patient experience are.

3.2 Choice of Data

In order to do this it was necessary to find data which offered a genuine insight into the patient's own experience of their terminal medical condition. The search for appropriate data raised numerous issues regarding availability of data, patient confidentiality, ethics, reliability and appropriacy. Fortunately, the desire to explore patient experience was intrinsic to the work of other researchers and practitioners. When met with the same issues, one organisation in particular had decided that it was necessary to establish a unique database of patient interviews with the purpose of researching and sharing patient experience.

In 2001 the Database of Individual Patient Experience 'Dipex' website was piloted. It was set up by Dr Ann McPherson and Dr Andrew Herxheimer whose personal experiences of illness had led them to conclude that despite their own medical

expertise, they needed a forum which went beyond theoretical knowledge to communicate and learn about the actual experience of illness. The aims of their website are reproduced below. [1]

- To share the experience of illness or a health problem and to provide support for patients and carers who may feel that they are on their own.
- Answer the questions and problems that matter to people when they are ill or have a health-related problem and to help them make informed decisions about their healthcare.
- Provide reliable, evidence-based information about illnesses or advice on health problems
- Be an educational resource for health professionals
- Promote better communication between patients and health professionals

To some extent the aims of that particular project coincide with the aims of the study. These are specifically, to analyse and compare advice versus reality: what as patients we are led to expect and how that compares to what we experience in the real world. In so doing, it may be possible to see whether or not there is such a thing as a 'model patient' role and how far patients conform to this role.

One way in which this can be investigated by examining the language used in both advice and interview data in order to determine the grammatical roles of the doctor, patient and other participants such as family members. A more detailed description of the linguistic tools employed will be outlined later but in general terms, an attempt has been made to measure the dynamism and power of the Patient in relation to other entities within the medical contexts of terminal illness. The examination of linguistic patterns in both the advice and interview data will help to establish whether there is parity of patient profiles across both data sets.

As far as the scope of the data is concerned, it was necessary to be selective in order to facilitate a sufficiently in-depth linguistic analysis. Given the richness of

data available via the Dipex website, it was considered more realistic to focus upon one general context of health and compare the linguistic patterns of the Patient interviews with those of the relevant advice texts.

3.2.1 Background to Data

As a result, the context of terminal illness was chosen. As outlined in the previous section, it is an area of medicine which poses numerous challenges for all concerned and has undergone recent developments in terms of both medical and social care. In addition, it is one where the doctor-patient relationship and the involvement of other family members are of prime importance. Finally, a key reason for this choice was that it is a situation where advice is often sought by patients but sometimes difficult for them to access directly. It could be argued that the availability of information and advice on terminal illness provided by the health service does not always meet patient demand and needs. It may be partly in response to this deficit that there has been a recent increase in information and advice material generated by patients, based upon patient experience and aimed at newly diagnosed patients. This patient-based information and advice is additionally aimed at medical practitioners in order to both provide 'an educational resource for health professionals' and to 'promote better communication between patients and health professionals'[1]. Therefore patient interviews offer a particularly valid insight into the experience of this health context.

The interviews selected were taken from one module of the Dipex website titled 'Living with Dying'[2]. Within this section there are 39 interviews with people of various ages ranging from 32 to 84. Interviewees are both male and female although the proportions are not equal with just over 41% male and just under 59% female subjects. In terms of sociodemographic background the respondents are all UK based, from a variety of backgrounds. To some extent this ties in with the medical contexts in that some of the interviewees' illnesses have been directly attributed to their previous occupation. However, this is not true in all cases. The table below provides a summary of the available patient interviews. 75% of the

patients interviewed for this section had been diagnosed with terminal cancer and so this was selected as the context of health. All interviews, as summarised below, were analysed according to Halliday's Transitivity System which will be outlined in the following section of this chapter.

Age	30-50	51-60	61-70	71-80	81-90
Number	5	10	15	7	2

Male	16
Female	23

A number of interviews, comparable to the advice data in terms of quantity, were then selected to compare with the advice texts. Analysed samples were selected from a range of age groups and genders and the details of the exact data corpus which was then concordanced can be found below.Overall a total corpus of over 87,000 words was analysed and concordanced. This can be presented more specifically in terms of the number of clauses analysed and concordance. It should perhaps be mentioned that originally a larger amount of interview data was originally analysed. However, for the purposes of parity, some of this was not included in the final results of the current study in order to ensure an equal distribution of analysed data from the advice and interview sources. Furthermore, the number of clauses concordanced is greater than the number of clauses which have been included for discussion in this thesis. The reason for this was to focus upon clauses in which patients appeared in roles with greater frequency, with a threshold of 5% of overall participation across all grammatical roles. As a result, clauses in which the patient appears in a grammatical role with a frequency lower than 5% were not included due to low incidence.

Data Source	No of clauses concordanced	No of clauses discussed within the current study
Advice websites	1420	1213
Patient interviews	1379	1238
Total	**2799**	**2451**

The interviewees were selected and conducted by Dipex in order to provide a representative sample of patients and their experiences using Coyne's (1997) method of purposive sampling. Interviews took place in the home generally but not exclusively and participants were able to have another person present if they wished.

The approach of Dipex interviewers was to start the interview by asking the person to describe their experiences from the point where their medical problem became apparent. The person's narrative could then be followed by a series of semi-structured questions. Audio and sometimes video recordings were made of the interviews which were then transcribed and analysed for common themes and possible future questions. This approach to interview design meant that the choice of questions and themes addressed were partly determined by the experiences and themes which emerged from the patient interviews. It should also be mentioned that not all parts of all the interviews appear on the website but rather edited sections. Equally importantly, the final say as to what can appear on the website rests with the interviewee who may request that certain sections do not appear.

The advice data was taken from a range of websites which offer guidance to patients and their families on living with terminal cancer. An attempt was also made to take into account data from more than one cultural context and health system. Therefore the corpus of advice data includes texts selected from more than one country, from comparable organisations and websites in both the UK and US. This has meant that advice on similar themes such as 'telling your children' can be examined within more than one cultural context and from the perspective of

multiple related organisations such as Cancer Research UK, Macmillian, Oncolink and the National Cancer Institute. These websites share the common goal which is to offer advice on various aspects of the illness, treatment and living with a diagnosis of terminal cancer. A full list of the advice websites included in the current can be found in the references [3-9].

A number of common themes appear within the interviews and advice data and these will be explored more fully when examining the results of the linguistic analysis. A sample of these includes topic areas such as:

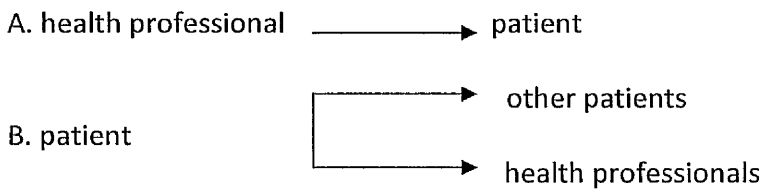
- receiving your diagnosis
- telling your family
- treatment decisions
- day-to-day living
- end of life decisions

The above brief outline of some of the main recurring themes indicates that there is some overlap between experiences which are described by patients in their interviews and areas which are addressed in advice sections of other health information websites such as Cancerbackup, Cancer Research UK and NHS Direct.

However, in general, the advice needs of patients with terminal illness can be characterised as unmet. In fact, the experience of terminally ill patients is often that the extent to which official advice is readily offered by health professionals is less than ideal. In this context it was found that no single medical advice website addressed these areas as comprehensively as the Dipex website patient interviews. This may be significant as it suggests that the lower availability of official and practical guidance for patients across several different advice websites possibly makes the Dipex website a more convenient starting point for patients seeking advice.

It is also significant that patient experience and patient interviews are becoming more popular and widely used not only by patients, but also by health professionals

as a learning resource for those who need to advise and communicate with patients. Whilst the more traditional advice from medical sources works in a simple one-way direction from medic to patient (as in A), the recent and more patient-based advice has a different configuration (as in B). The advice here is taken from individual patients and is aimed in two directions towards both other patients and health professions. It can be seen below that changes have occurred in the source and direction of advice.



Therefore, the dual purpose of such material offers a rich source of data and a useful starting point for the researcher seeking to analyse representations of the patient in the context of terminal illness. As advice authorship changes gradually from being exclusively health professional to incorporate patient experience, the target audience of health advice broadens similarly to include health professionals. In addition to changes in the source and direction of advice, it is worth considering how far the aims of such advice and the nature of the representations contained may also have changed. This study aims to investigate whether and how far the linguistic patterns of traditional advice texts from medical sources vary compared with more patient-based advice from patient interviews.

As outlined in the previous chapter, there has been a great deal of investigation within health research, medical sociology and communication studies into the nature and characteristics of medical discourse. A more recent area of enquiry has been to explore patient experience through the examination of patients' narratives and language. The most basic assumption now seems to be that the best way to find out about patient experience is to ask the patient to tell you about his or her experience. Qualitative health research has approached this in a number of ways as

outlined in the previous chapter. A point of particular relevance to this study is that within this framework patient experience is being analysed via the patients' own language. What is already being investigated in health research can be offered a more linguistic approach through the application of transitivity to patient language. The key points of how and why a linguistic approach can be applied in order to address questions posed by health research can be summarised below.

Transitivity as Applied to Health Communication Research

- Experience can be decoded through analysis of language.
- Transitivity takes a structured grammatical approach, examining the processes each entity participates in and the grammatical roles they occupy.
- There is a system of decoding but also a degree of interpretation of language.
- Process of decoding experience can help us to better understand lived experience.
- This understanding leaves us better informed and also equipped to deal with the experience.
- Thus, to some extent, it can shape our experience.

What is perhaps noteworthy is that both health research and linguistic research are investigating the same question but using different methods and tools to find the answers. However, the aim is similar – to learn about patient experience through the analysis of the language choices which patients make when communicating that experience.

3.3 Linguistic Analysis of Data: an overview of the Transitivity System

To enable a detailed examination of the language used in both advice and interview data it was necessary to conduct an appropriate linguistic analysis of the data. More specifically an analysis of the transitivity patterns was carried out in order to determine the grammatical roles of the Doctor, Patient and Other participants such as family members. The following section therefore sets out in detail the essential points and aims of this approach and demonstrates how it can be used.

As described in the previous chapter, the transitivity system concerns itself essentially with the experiential function; how our experience of the world is encoded in text. This is revealed by examining closely the grammatical processes and participants within the language. As an analytical tool it has been widely used to uncover ideological assumptions conveyed through the linguistic choices we make. For instance, the same event will be both experienced and communicated quite differently by two different people and this will be evident in the transitivity choices they make in representing their experience.

Thus in relation to this particular study the transitivity system enables the analyst to highlight the grammatical processes and roles of participants within the specific contexts of medical advice texts and interviews. In so doing it is possible to examine more closely how the people involved in those medical situations represent their experience of them. To be more specific, it is possible to decode grammatically how the world of illness is construed by such texts. For example, by examining how far patient feelings are represented and what those feelings are, insights may be gained into the emotional aspects of illness as denoted by advice texts and patient interviews.

It is also possible that this understanding may influence patient experience as these texts are generally accessed by patients or family members seeking advice on what to do or what to expect in a particular context of health. An example of this might be when seeking advice on 'telling your children about your illness'. This advice may

be sought through official advice texts or by accessing patient experience as a potential model. In either case, the information provided will probably relate to the patient, their children, their partner, their illness and the future. Within that framework there will be a number of actions or processes which occur such as what to say, how the children may react, what to do or say when they ask questions. Each of these can be analysed separately to identify who is saying what or who is feeling or doing what. Collectively they construe a small part of the world of illness: the part in which the illness has to be explained, reactions felt and dealt with and plans made for the future. With one of the key aims of these texts being to advise patients on what to expect and how to behave, it may be fair to argue that the way in which living with terminal illness is represented and construed can have a direct bearing upon how is experienced. Furthermore, the fact that this advice or experience could have been otherwise encoded should not be overlooked as the fact remains that the writer or speaker's linguistic choices are a manifestation of the world of illness as represented by the speaker or writer.

Additionally, it may be possible to determine whether the transitivity patterns of patient advice and patient interviews correspond and in this respect, how far and in what ways they bear linguistic similarities or differences. Finally, it can provide a clear analysis of the relationships between people as encoded in grammatical patterns and the degree of dynamism or control accorded to them within the context of health and illness. This matter will be explored later in the chapter when describing the concept of 'dynamism' and its significance with transitivity analysis.

Processes can be ascribed to one of six general process types (Halliday, 1994) each of which involves certain participants. In very general terms, the division of process types and participant roles make it possible to discern what is happening, who is doing it and who they are doing it to. Each of the six basic process types is outlined below with examples taken or adapted from the current data. Within each of the six basic process types there are further categories which offer a more delicate analysis of what is taking place between the entities involved. The following

section, based on Halliday (1985), Halliday and Matthiessen (2004) and Thompson (2004), also explores how these finer distinctions can be made.

3.3.1 Process Types and Participants

Material processes involve actions and events. They are often acts of 'doing' such as going but are also events taking place or happening such as flooding. Material processes require a 'doer'; referred to as an Actor and often involve a 'done to'; known as a Goal. Whilst it is necessary for all material processes to be carried out by an Actor, it is possible for it to occur without a Goal as in the second example below. Thus, it is possible to distinguish between a 'middle' process which is carried out by an Actor but has no Goal and a 'non-middle' process which involves both Actor and Goal (Berry, 1977) as in the first example.

...an electrician	brought	the heater and fitted		it...
Actor	**material process**	**Goal**	**material process**	**Goal**

...the mentor	would come in...
Actor	**material process**

There are a number of different ways of sub-categorising material processes (Halliday and Matthiessen, 2004). One of the most relevant for the present study is the distinction between categories of material process which are either intentional or involuntary. A further distinction can be made between actions which are carried out by a conscious Actor as opposed to a non-conscious Actor as in the following examples. In the first instance there is a material process carried out intentionally by a conscious Actor. The second and third cases show material processes carried out involuntarily but a conscious and non-conscious Actor respectively.

I	went	to the clinic
Actor	**material process**	**Circumstance**
conscious	**intention**	

I	had lost	a lot of weight
Actor	**material process**	**Scope**
conscious	**involuntary**	

...the cancer	had spread...
Actor	**material process**
non-conscious	**involuntary**

A further point to mention is that the distinction between intentional and involuntary may also be context specific. In the second example above, 'I had lost a lot of weight' has been analysed as involuntary because it is mentioned as a side effect of the speaker's illness. However, in a different context, one where the speaker has actively made an effort to achieve weight loss perhaps, this process could be analysed differently.

I	had lost	a lot of weight
Actor	**material process**	**Scope**
conscious	**intention**	

In addition to distinguishing between voluntary and involuntary materials processes, there is a further sub-categorisation of material processes which depend upon how the process impacts upon the Goal. Two types of material processes can be identified; namely creative processes whereby the Goal is created by the process or transformative processes in which Goals are simply acted upon by the process.

I	write down	a list of questions and points...
Actor	**material process**	**Goal**
conscious	**intention**	
	creative	

...I	protect	my family and my partner...
Actor	**material process**	**Goal**
conscious	**intention**	
	transformative	

Similarly to the categorisation of Actors, Goals can also be considered in terms of whether they are conscious or non-conscious or, more usually, whether they are animate or inanimate. This distinction may be worth exploring where, as in this study, there is an interest in how human Actors are acting and how far that impacts upon other people or entities within the medical framework. Thus the dynamism of the Actor can also be determined by the type of Goal it is acting upon as in the following examples.

...people	you	leave behind...
Goal	**Actor**	**material process**
animate	**conscious**	

...I've	signed	the documents...
Actor	**material process**	**Goal**
conscious		**inanimate**

Having outlined the most frequent and varied of all the process types, the next major type of process is Mental processes. These typically involve thinking or

feeling. There are two main participants within this group which are the Senser; responsible for the act of sensing and the Phenomenon which is being sensed.

... I	enjoy	life...
Senser	**mental process**	**Phenomenon**

As with material processes, mental processes can also be divided. There are four basic types of mental process relating to acts of cognition, perception, emotion and desideration (Thompson, 2004). The first category includes processes of logic, thinking, reasoning, decision and comprehension. In contrast, the second relates to how we perceive things in terms of senses such as sight or sound. This is as opposed to the third class which covers how we feel emotionally about a phenomenon or how we may react to it. Finally, desideration involves the process of wanting or desiring. The four types of mental process are exemplified below.

...my wife **Senser**	doesn't understand **mental process** **cognition**	all the financial dealings of the family... **Phenomenon**
...she **Senser**	feels **mental process** **perception**	the tingling... **Phenomenon**
...we **Senser**	fear **mental process** **emotion**	death... **Phenomenon**
I **Senser**	don't want **mental process** **desideration**	a life hereafter. **Phenomenon**

Furthermore, there are alternative ways in which a process can be configured so that it is possible for a Phenomenon to act upon Senser rather than the more typical arrangement of the Phenomenon being sensed by the Senser.

The treatment	worried	me.
Phenomenon	**mental process**	**Senser**

The third main class of process is that of Relational processes. These can be broken down into processes of being or having and are generally related to states rather than actions. They differ from material processes in that they are used primarily to describe things in terms of their qualities and identity rather than to talk about actions taking place in the world. There are two types of relational process which are known as attributive and identifying. The first type is concerned with describing the qualities of a particular person, place or thing and is known as an attributive relational process. The two key participants within this type of process are the Carrier and Attribute. The Carrier refers to the person, place or thing which is being described, whilst the Attribute relates to the qualities which are assigned to that person, place or thing. The other type of relational process is used to identify one thing in relation to another and is known as an identifying relational process. It involves the participants of Token and Value: the Token can be seen as a specific example or representative of a more general category known as Value. The difference between the two types of relational process can be shown by the following examples.

The doctors	are	very specialised
Carrier	**relational process attributive**	**Attribute**
...whether it's		my GP or a consultant that I've seen...
Value	**relational process identifying**	**Token**

Whilst material, mental and relational processes tend to be the most prominent, there are three remaining process types which can be found. The first of these is verbal which essentially is concerned with the passing on of messages or information. This process type requires the participant of Sayer and often also that of Receiver. The Sayer refers to the participant delivering the message and the Receiver is the person who is told or given it. The message being communicated is referred to as Verbiage. An additional role to Receiver and Verbiage is that of Target. This participant differs from Receiver in that it is the person or thing being talked about rather than to as highlighted in the following two verbal processes.

I	haven't asked	them	specifically how many years...
Sayer	**verbal process**	**Receiver**	**Verbiage**

I	can voice	my feelings...
Sayer	**verbal process**	**Target**

A further category is that of Behavioural processes. These can be regarded as operating somewhere between material and mental processes. Actions which are of a physiological and often involuntary nature such as breathing and sleeping are typical examples of this group. In many cases behavioural processes are a more physical manifestation of mental processes as can be seen by comparing the following two examples.

I	look at	the sun...
Behaver	**behavioural process**	**Range/Behaviour**

...I	actually saw	all the sort of horrid details...	
Senser	**mental process perception**	**Phenomenon**	

The final process type is known as Existential and accounts for the least frequent group. This group comprises processes which are concerned with existence or a lack of it. This is as opposed to relational processes which contain additional elements such as identity or attributes. Existential processes are those which simply express whether something exists or not and can mostly be easily identified by the use of 'there is'. There is only one key participant in an existential process, that being the Existent.

... there is	a gastroenterology specialist...
existential process	**Existent**

In addition to the processes and participants detailed above, there are a number of other participants which may also appear within a transitivity analysis. Several of these participant roles operate across process types although there are some particular cases which are process specific. Despite the fact that certain participants are of low frequency, they are of interest and worth summarising briefly. The first of these is known as an Initiator and can be summed up as a participant which initiates or causes another process to take place as in the example below where 'I' initiates the verbal process which follows. Initiators can instigate material, mental, verbal and behavioural processes. An important feature to note with the Initiator in this example is that grammatically the main process is to 'make sure'. However, it is not possible to determine the nature of the main process even though the purpose or outcome of the action becomes more evident later. Despite the extra information about the following verbal process, it still remains unclear exactly what the Initiator in this sentence did other than initiating the verbal process which it precedes.

I	make sure that they	answer those questions.
Initiator	**Sayer**	**verbal process**

In a similar way there is a specific participant which plays a causative role in relational processes. The role of Attributor is occupied by a participant which causes an attributive relational processes and its equivalent in identifying processes is known as an Assigner.

... they	will keep	me	here at home...
Attributor	**relational attributive**	**Carrier**	**Attribute**
My illness	has forced	her	to be the head of the family.
Assigner	**relational process identifying**	**... Token**	**... process ctd.** **Value**

In contrast to participants which cause processes to occur, a further category entails those which are merely a part or extension of the main process. In this sense they are roles which cannot function independently of the main process to which they are attached. These are generally referred to as Range but can be divided into different types according to process type. For example in behavioural processes the Range is termed Behaviour whereas in verbal processes the role of Range is occupied by Verbiage and in mental processes it is known as Phenomenon. In general the highest incidence of Range occurs with material processes, in which case it is referred to more specifically as Scope. In the example below 'the epidural' is tied to the verb 'to have' in that together they describe a material process. By itself 'the epidural' does not describe an entity to which the process is 'done' (as is the case with Goal) but is a key component in the process. Equally, in this particular example the process of 'had' makes very little sense without the accompanying Scope to explain precisely what process the Actor is participating in.

...I	had	the epidural...
Actor	**material process**	**Scope**

In some processes there is an additional participant which appears to be neither doer nor the done to. This can be described as the participant for whose benefit the process occurs and it can be broadly labelled the Beneficiary. Finer distinctions can be made according to whether the process is encoded as happening 'to' or 'for' the Beneficiary as in these two instances:

...they	gave	a sedative	to me...
Actor	**material process**	**Goal**	**Beneficiary** **Recipient**

your GP or social worker	can arrange	an appointment	for you.
Actor	**material process**	**Goal**	**Beneficiary** **Client**

Finally, the background against which processes may take place is labelled Circumstance. It does not have an active role in the same way as other participants but nevertheless provides useful information about matters such as location, manner, time and attitude. Circumstances are relevant to all process types and frequent in their appearance. The example below demonstrates how a person can be situated within the Circumstance within a clause. This is a choice which will be returned to later when exploring the notion of dynamism.

...they	put	the needle	in me...
Actor	**material process**	**Goal**	**Circumstance**

3.3.2 The Transitivity System: Complexities

The above section has outlined the six main process types found within the transitivity system. Each type has a distinct function in terms of representing types of meaning and our experience of events in the world. They also serve to represent the relationships between people and entities participating in those events. However, to suggest that all processes fall easily within one class would be misleading. The allocation of a process to the relevant category can often depend upon the context in which it occurs. This means that the same verb may be allocated to a quite different process type when viewed within another context. For instance, the verb 'get' can be analysed in more than one way.

I	get	upset	very easily.
Carrier	**relational process**	**Attribute**	**Circumstance**

I	got	a letter	from the hospital.
Actor	**material process**	**Goal**	**Circumstance**

In the first case 'get' is labelled as a relational process because it carries the meaning of 'become' and the second participant is an adjective 'upset'. In contrast, the second example uses 'get' with a material meaning as in 'receive'. Thus, it is not possible to claim that all lexical verbs can be assigned exclusively to a single process type given that several may be interpreted in two or more ways according to the context in which they are used.

In addition it may be that a particular process within a distinct context cannot be allocated to one specific type with certainty because it contains significant elements of another process type also. Processes such as this can be regarded as blends or borderline and a very good example of this from the current data would be 'to

diagnose' which could be analysed in the following way where the process of diagnosing an illness involves certain mental processes such as considering evidence and decision making.

I	was first diagnosed	in the hospital...
Phenomenon	**mental process**	**Circumstance**

However, it could be argued that there are also material and verbal elements involved in the processes of carrying out tests, naming a condition and informing the patient. Ideally, the context will indicate which process type predominates. However, it cannot be denied that there are elements of at least three process types built into the action of diagnosing. This typifies the kind of process where there may be disagreement even amongst experts as to how it should be classified. For this reason, in some contexts it may be very difficult to decide which process type is the most appropriate. One course of action may be to simply acknowledge that it is a borderline process and choose the process type which predominates according to context. Where this proved impossible, it was felt necessary to analyse it as a process blend with more than one set of labels attached as in the example below. The first analysis treats 'get' as meaning 'to experience' a pain whereas the second reading interprets it as 'to have' a pain.

I	got	a pain
Actor	**material process**	**Scope**
Carrier	**relational process**	**Attribute**

In addition to borderline processes and process blends, there is a further way in which process type overlap may be evident. This relates to processes which contain overtones of another process type. The following process demonstrates how a mental state is encoded grammatically in a relational process. It is analysed as a relational process because 'guilty' is an adjective which refers to a mental state.

Therefore, in relation to the current study, this can be handled by establishing the sub-category of mental attribute as in the example below.

I	feel	guilty...
Carrier	**relational process**	**Attribute (mental)**

The earlier example of 'diagnose' also demonstrates a less problematic feature of wording. This relates to invisible participants which are understood to exist but simply do not appear in the clause.

I	was first diagnosed	in the hospital
Phenomenon	**mental process**	**Circumstance**

It can be assumed that the process of diagnosing was carried out by a person and that that person was medically qualified to do so, yet it is not always necessary to mention them. This is often because certain verbs have an inherent type of doer, so that in a sense that participant may not need to be mentioned unless there is a special reason to do so. This is true of a verb such as 'diagnose' where only a medically trained doer could carry out such an action. Despite not being visible in this example, the Senser does exist within the process and so this process can be rewritten with the Senser reinstated.

I	was first diagnosed	*by the consultant*	in the hospital...
Phenomenon	**mental process**	**Senser**	**Circumstance**

It is also worth noting that events and experiences could also be expressed in a number of different ways as in the examples below which involve different process types and changes in the participant roles of both the patient and the treatment.

I	was worried	by the treatment.
Senser	**mental process**	**Phenomenon**

I	was	worried	about the treatment.
Carrier	**relational process**	**Attribute (mental)**	**Circumstance**

This clearly demonstrates a key point raised earlier when discussing the notion of choice in that there are alternative ways in which the same event can be encoded. The use of Circumstance to position 'me' in the following example is of interest in that the same event could be encoded otherwise as in the second example which offers a rather different interpretation and emphasis.

...they	put	the needle	in me...
Actor	**material process**	**Goal**	**Circumstance**

I	had	an injection.
Actor	**material process**	**Scope**

In the first example the patient provides the circumstance or background against which a medical procedure is carried out by medical professionals. In this instance the medical professionals participate as Actors whereas the patient does not participate actively. However, in the second example the medical professionals are notable by their absence and although the patient does not administer their own injection (as in 'I injected myself'), they nevertheless take the grammatical role of

Actor on this occasion. This ability to encode and represent the same event in very different ways is a manifestation of the choices made by a particular speaker or writer. It is a matter which requires further expansion within this section, particularly in conjunction with the concept of dynamism which is central to the aims of this study in examining representations of medical experience.

3.3.3 Dynamism

As outlined in the previous chapter, dynamism can be broadly defined as the degree of control or efficacy with which a participant is invested. Dynamism is concerned with who does what to who and how the actions of one participant may (or may not) affect another participant. It is therefore possible to regard certain participant roles as more active, dynamic and effectual upon other participant roles. The reverse is also true in that some participant roles may occupy a more passive, undynamic and ineffectual position in relation to other participants. The two earlier examples, repeated below, involved the speakers at the extreme ends of the dynamic scale, firstly as the Circumstance and secondly as the Actor. These two versions of the same event represent the speakers in very different participant roles and therefore affecting or being affected by the material process in which they are involved.

...they	put	the needle	in me...
Actor	**material process**	**Goal**	**Circumstance**

I	had	an injection.
Actor	**material process**	**Scope**

In the first case 'me' appears as a Circumstance, the thing or place into which needles are put. The 'me' in this process has no effect upon another participant and

is significantly lacking in dynamism. In contrast, the second example presents 'I' is more actively involved in doing something by having an injection, rather than having it done to 'me'. The speaker in this process has encoded their experience of this event quite differently from the first speaker. They are participating in the process as an Actor and thereby possessing greater dynamism. Although the Actor in this example may not be having an effect upon other participants, the fact of acting rather than being acted upon necessitates a more dynamic participatory role. In very broad terms an Actor (doer) is invested with greater dynamism than a Goal (done to).

With this in mind it is possible to consider the degree of dynamism across a range of participant roles from the most to the least dynamic. The scale in use here is based upon Hasan's original cline as set out in the previous chapter. However, it has been updated in order to accommodate revisions to participant roles and the arrangement of the cline itself. These revisions are firstly the result of the inclusion of additional participant roles. In certain cases this has been due to a revision of existing labels such as in the case of Scope (rather than Range). In other instances revision has arisen from new categories and participant roles. Examples of such developments are Assigner, Initiator and Attributor, all of which have been added since Hasan's (1985/1989) original cline was drawn up.

Secondly, with the addition of new participant roles it has become necessary to revise the arrangement of the cline from active to passive in order to accommodate additional participants not included on the original cline. The original arrangement has since been revisited by Thompson (2006) and similarly in this study the positioning of participants along the cline of dynamism varies from Hasan's original in places. These position revisions will be detailed shortly upon presentation of the most recent version of the full cline with examples.

As mentioned previously, generally speaking the range of roles can be placed on a scale of high, medium and low dynamism, although it must be acknowledged that these terms are intended only as an approximate guide at this stage and are not

necessarily problem-free owing to their potentially subjective nature. An initial division of some common participant roles within these parameters is outlined below.

Participant Role	**DYNAMISM**
↓ Assigner / Initiator	**HIGH**
Actor + Goal	**MEDIUM**
Actor – Goal and/or + Scope	**LOW**
Behaver	
Sayer	
Senser	
Token	**ZERO**
Carrier	
Beneficiary	**MINUS**
Phenomenon	
Scope	
↓ Goal	

Fig. 6 Cline of Dynamism *Based upon Hasan 1985/1989*

As shown above, there are fewer roles of high dynamism and more within the medium and low groupings. In addition, it demonstrates that differing degrees of dynamism may be invested in the same participant role depending upon the overall configuration of the process. For example, the dynamism of an Actor is greater if it is acting upon a Goal as opposed to acting without a Goal as in the following examples taken from the same interviewee.

I	was working...	
Actor	**material process**	

...I	was...managing	my family...
Actor	**material process**	**Goal**

The first example is one in which the Actor is experiencing a material process and doing something, in this case work, but having no direct effect upon anything or anyone else within that process. The second example differs in that the Actor here has an effect upon the Goal (her family) by managing them.

The dynamism of an Actor acting upon a Goal may also be greater if the Goal is animate rather than inanimate. When looked at from this perspective, the following two examples contain Actors with an apparently increasing degree of dynamism. The first instance shows an Actor involved in a process which affects an inanimate Goal – 'a list of questions'. In contrast, in the second example the Actor acts upon the animate Goal of 'people'.

I	wrote down	a list of questions.	
Actor	**material process**	**Goal (inanimate)**	
I	will leave	people	behind....
Actor	**material process**	**Goal (animate)**	**Circumstance**

However, there is some debate as to how far this is always the case and whether the animate or inanimate aspect of a Goal has such a straightforward or significant impact upon dynamism. The same two examples above could be interpreted differently in that the Actor involved in the creative material process of 'writing down' a list of questions could be considered as more dynamic than the Actor in the transformative material process of 'leaving' people. Leaving aside the animate/inanimate distinction of the Goal and focussing instead on the nature of the material process, it could be argued that 'writing down' or producing something is more dynamic than 'leaving' or going away from someone. In the first case the 'list of questions' has been brought into existence and it therefore may be an oversimplification to argue that because the Goal here is inanimate, the degree of

dynamism is lower than if it were animate. The questions raised by these conflicting interpretations exemplify a key consideration within any transitivity analysis, particularly concerning dynamism. These two examples demonstrate that to analyse a process and participants without taking into account lexical as well as grammatical choices and the interplay between them, would be to provide an incomplete picture of the language choices made.

Although there are complexities involved in assessing dynamism, the essential concept when applied to transitivity asserts that there is a basic difference in terms of affecting the world around us between participating as an Actor and as a Goal. It is on this basis that distinctions can be made in terms of the high, medium and low dynamism of a range of participants as shown earlier.

In view of this, finer distinctions can be made and it is possible to place a representative sample of participants along a dynamic scale ranging from the most to least dynamic. The following scale is based upon Hasan's model (1985/1989) with revisions suggested by Thompson (2006) and with some more delicate sub-categories that will be relevant to my own study. The reason for implementing these revisions is in order to allow for more delicate qualitative distinctions within the analysis as well as a broader quantitative analysis of the categories found within the data.

Dynamic

↑	Assigner / Initiator	...the thought of a life hereafter makes me shudder to be honest.
	Attributor	... they will keep me here [at home]...
	Actor (+ animate Goal)	I will...push them (the doctors).
	Actor (+ inanimate Goal)	I write down a list of questions and points
	Actor (– Goal or + Scope)	...to make sure I didn't overdose...
	Phenomenon (Subject)	I (don't want to) upset anybody.
	Behaver	... I woke up in the Intensive Care Unit
	Sayer + Receiver	Well I haven't asked them specifically how many years...
	Sayer + Target	...I can voice my feelings...
	Sayer	...when I say it doesn't bother me...
	Senser	I don't know (regarding euthanasia)...
	Senser + Phenomenon	Somebody (this mentor) who knows about all the contacts...
	Token / Value	...whether it's my GP or a consultant that I've seen...
	Carrier	... both my wife and I had up to date wills in place.
	Beneficiary	I could give myself a shot of morphine...
	Phenomenon (Complement)	I want my friends and family round me...
	Scope	... when you're seeing a consultant...
	Goal/Target	... somebody wanting to get rid of their relatives...
↓	Circumstance	... they put the needle in me...

Passive

Fig.7 Cline of Dynamism *2012 Version Based upon Hasan 1985/1989*

The main revisions to the cline can be divided into three main types. The first and simplest of these is where a participant role has received a new label as in the case of Scope replacing Range. Further additions such as Assigner, Initiator, Attributor, Token, Beneficiary and Phenomenon (as complement) are examples of previously existing participant roles within the transitivity system which did not appear on the original cline. Each of these has been added at a suitable position in relation to other participant roles in terms of dynamic value.

The third type of revision relates to changes in the arrangement or positioning of participants along the cline ranging from passive to dynamic. The first and most obvious change is that the most dynamic position is now occupied by the roles of Assigner or Initiator and Attributor rather than Actor with a Goal. This is due to the fact that these roles are involved in causation rather than effect, and cause other processes to take place. The next noticeable changes of position relate to the roles of Actor without a Goal or with Scope, Behaver and Phenomenon as subject which now appear slightly further up the dynamic scale than previously. An Actor without a Goal or with Scope now appears closer to an Actor with Goal. All three of these repositioned roles now appear above Sayer as they are involved in acts of doing or acting upon another entity. The final change of position relates to Scope (labelled Range on the original cline) and Goal which have switched position as Goal is being acted upon and is therefore considered less dynamic.

In terms of dynamism these changes of position are felt to indicate a more comprehensive and accurate sliding scale with participant roles in closer proximity to those with which they are more closely related in terms of their dynamic nature. However, it remains to be seen whether all of these changes in position actually signal an alteration in the dynamic value of these participant roles significantly. At this stage the only roles which seem to have changed in terms of dynamic value are at the top and lower end of the cline. Actor no longer has the highest dynamic value and has moved down the cline to be replaced by Assigner or Initiator. At the passive end of the cline Goal appears to be lower and Scope now appears slightly less low than previously.

Overall it can be seen that the repositioning of participant roles along the cline of dynamism appear to have affected the dynamic value of some participant roles at the two extreme ends of the scale but has less impact upon the dynamic value within the intervening points. The question of dynamic value can be considered in more detail when assigning participant roles to broad bands and allocating scores. A further more general change to the overall cline of dynamism is that the numbering of levels from 1 (dynamic) to 13 (passive) has been dispensed with and

will later be replaced with a system of banding and scoring which will be demonstrated below.

The fact that the table above appears to be straightforward is not to imply that the scale of dynamism is unproblematic. In truth it is only through the application of this scale to real data that the scale can be carefully tested. In some respects it may be more useful to consider the scale as a more detailed version of the high, medium and low bands outlined previously and to divide the more detailed cline above into broad bands as follows.

Dynamic	
↑ Assigner / Initiator	**HIGH**
Attributor	
Actor (+ animate Goal)	**MEDIUM**
Actor (+ inanimate Goal)	
Actor (– Goal or + Scope)	**LOW**
Phenomenon (Subject)	
Behaver	
Sayer + Receiver	
Sayer + Target	
Sayer	
Senser	
Senser + Phenomenon	
Token / Value	**ZERO**
Carrier	
Beneficiary	**MINUS**
Phenomenon (Complement)	
Scope	
Goal/Target	
↓ Circumstance	
Passive	

Fig. 8 Cline of Dynamism with Bands

However, the problem still remains of how to use these concepts practically in order to compare the dynamism of different entities in a text. One approach might be that since it is possible to calculate how frequently each agent such as doctor or patient occupies a particular participant role, the tool of measuring dynamism

allows the analyst to determine how much dynamic value is assigned to each of the entities involved within the data. The process of measuring dynamism will be demonstrated later when outlining the practicalities of the analysis and the application of a weighting system to the cline of dynamism (Thompson, 2006).

Thus far certain considerations arising from the analytical approach have been outlined. Several of these will be returned to and expanded upon later in relation to the findings of this study. However, these complexities, particularly those of a linguistic nature such as process blends, should not be considered as problems or obstructions. They are an inherent part of the task of unravelling language and decoding meaning - both of which by their very nature require a degree of interpretation as well as identification. In this respect linguistic complexities are points to be explored because complexities in the analysis can be said to reflect complexities in the way speakers are representing the world.

Therefore, despite the fact that transitivity can sometimes raise several questions and puzzles for the analyst, it is possible to carry out a detailed analysis of the transitivity patterns within text. This process can be carried out using computer software; however it was felt that a manual analysis would be more beneficial in order to deal with some of the subtleties mentioned above.

3.4 Methodological Considerations

3.4.1 Context and Comparability of Data

To accompany the relevant theoretical points, mention should also be made of some of the practicalities of the analysis and methodological considerations. The first of these concerns the context and nature of the data itself. This is particularly relevant given the importance of context to language as a system of choice as discussed in the previous chapter. It is also worth exploring in relation to the current data in order to indicate how the role of context can inform the choices of language users.

In linguistic terms, context relates to the 'context of situation' (Halliday, 1985, p12) and is comprised of three core components: the field, tenor and mode. These correspond to what is taking place, the participants and their relationship and the language in use. In relation to the current data the field can be described as health advice or experience and this is probably the most straightforward of the three components.

The tenor is concerned with the participants, their relationships and the social distance between them. These issues, having been explored with regard to the sociology of medicine and research background in the previous section, can now be extended to include a specifically linguistic approach to participants, relationships and social distance in medical discourse. Within the current data the advice texts are less complicated than the patient experience interviews. The advice texts have been written by medical experts and are generally read by patients or carers seeking expert advice and information. The participants and their relationship can be viewed as institutional within the situation of medical advice, hierarchic in that the advice is passed from expert to non-expert thus creating a maximal social distance.

TENOR

Health Advice: Medical expert → Patient or carer

Institutional, hierarchic, maximal social distance

However, the tenor is sometimes complex in its arrangement since the participants appear to engage on more than one possible level. This complexity is more evident in the relationships and social distance within the patient experience interviews whereby the patient is interviewed by a Dipex interviewer who then selects extracts which are made available on the website to other patients. In some respects the interviewed patient may be regarded as an expert patient usually more experienced in living with that particular health condition. The interviewer is also equipped with expertise in their field of health and health research and although the interviewers at times appear to defer to their interviewees' experience of being a patient, the fact remains that they are part of the medical profession and are therefore experts of a different kind. As experts within the medical establishment, it could be argued that their expertise is regarded as higher than that of their expert patients on the hierarchic scale of expertise. Finally, it may also be argued that the second patient accessing the website is perhaps equally likely to be either an expert patient or non-expert patient as the website is designed as a means of advice and support through shared experience.

TENOR

Health Experience: Expert patient → Medical expert → Patient (expert/non-expert)

Institutional, hierarchic, maximal / ≈ social distance

This arrangement of tenor connects with Berry's (1981) system of knowledge transfer and information exchange whereby there is a distinction between the 'primary knower' who has ownership of the information being transferred and the 'secondary knower' who receives the information. This basic distinction has been refined further (Berry, 1987) to account for the 'PRIMARY KNOWER' who is an expert within a general field and the 'primary knower' who is an expert within a specific field. This division distinguishes between types of knowledge such as medicine in general (a doctor) and specific medical symptoms (a patient). In this respect, it can be argued that both parties are experts of their own field but not necessarily of each other's. It is also worth noting the + or - distinction to show presence or absence within a particular knowledge role. In Berry's term, this is largely dependent upon the type (or types) of knowledge each is expected to possess. With this in mind, it can be argued that these labels could be applied to the above arrangement of tenor as follows.

TENOR

Health Experience

Expert patient + primary knower / - PRIMARY KNOWER

↓

Medical expert + PRIMARY KNOWER / - primary knower

↓

Patient (expert/non-expert) + primary knower / - PRIMARY KNOWER
secondary knower

Fig. 9 Tenor in Patient Interviews

The third contextual element relates to the mode or type of language used. Mode can be further subdivided into three constituent parts of channel, medium and

function (Hasan, 1985). The first of these refers to how the message is expressed, whether written or spoken. The medium relates to the linguistic patterns employed and whether they are more typical of written or spoken language. Finally the function is concerned with the purpose of the language being used and whether this is 'ancillary', to accompany an action, or 'constitutive', performing an action (Hasan, 1985, p57). In the current context it can be regarded as both in that language performs the action of relating patient experience and giving patient advice as well as accompanying further action, such as modifications to behaviour, which may be carried out in response to advice. In simple terms, mode can be summarised as in the following formula and diagram:

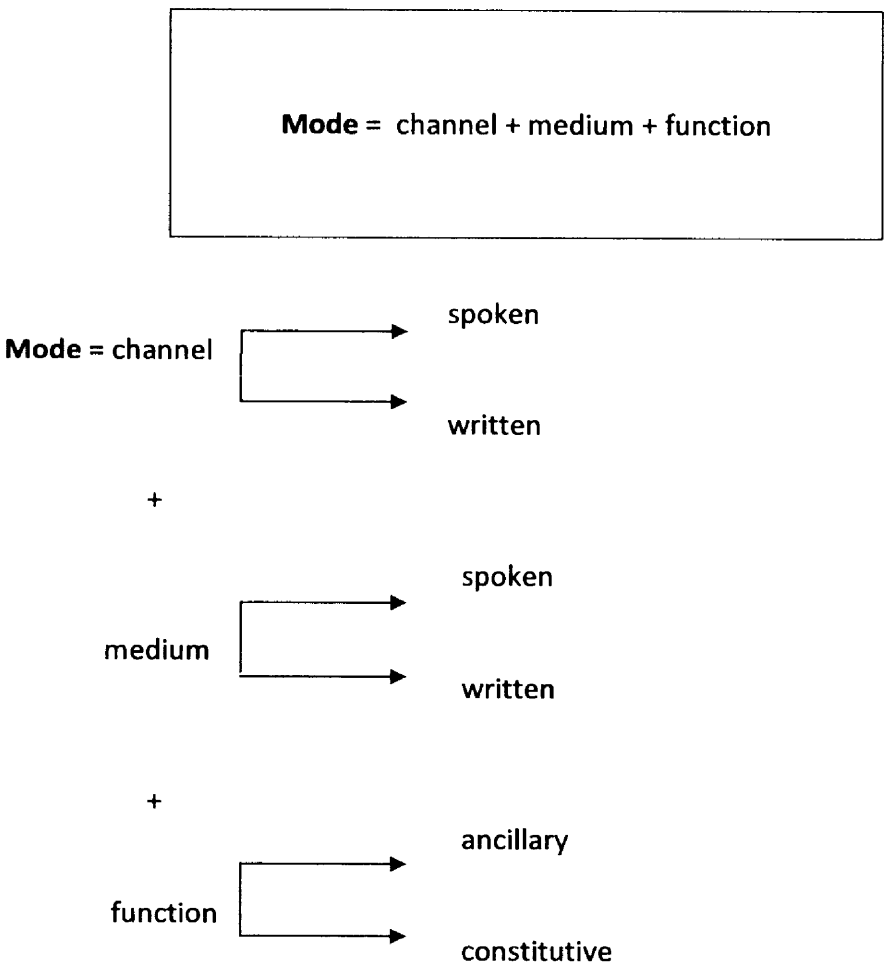


Fig. 10 Mode in Patient Interviews

When applied to the current data this framework is not as clear cut as the diagram above suggests. For example, the channel differs between advice and experience texts given that they are communicated through writing and speaking respectively. Therefore, it can be argued that the diagram above does not adequately take into account the different contexts within which these two text types are placed and the levels on which they operate. A more helpful approach may be to consider the text types within their two different contexts as follows.

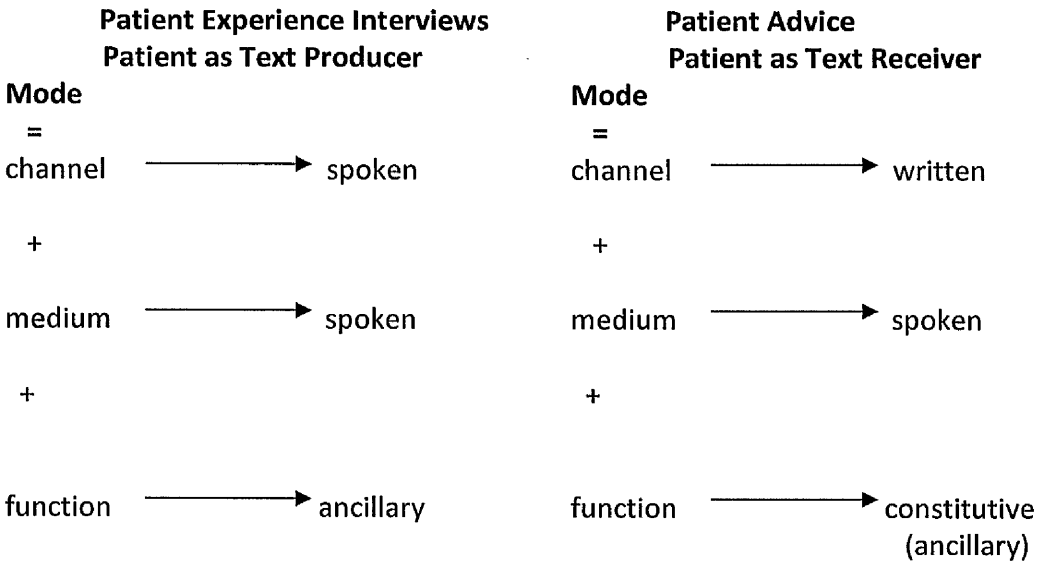


Fig. 11 Mode in Patient Interviews and Advice Data

Analysing context according to the role of patient as text producer or text receiver also permits some flexibility when considering the same text from both vantage points. For example, the Dipex interviews operate as representations of patient experience whereby a patient tells their story. Although it cannot be assumed that this is necessarily the case, it is possible that the same interviews may be accessed on the website by other patients seeking advice based on the experience of their fellow patients. This leads to the potential for a dual function of the patient interviews as suggested below.

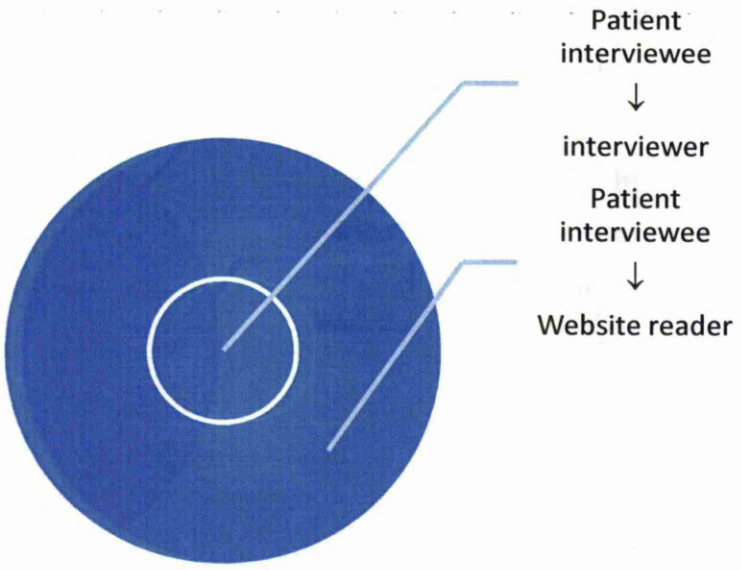


Fig. 12 The Dual Function of Patient Interviews

Despite these complexities which will be dealt with in more detail when considering the analytical results, there are certain generalisations which can be made regarding the data. As a rule the advice texts have been taken from website pages which have been written and edited by professionals. The data on patient experience has also been taken from an internet source. However, it is based on spoken interviews which were later transcribed and uploaded on to the website. To some extent it is possible to broadly divide the data since the advice sections have been produced in writing whereas the interviews were conducted orally.

CHANNEL

Advice ↔ **Written** (or graphic)

Experience ↔ **Spoken** then written

However, a closer inspection of the medium or language patterns of the data reveals a more complex combination of spoken and written qualities. To be more precise, there is a degree of overlap in that the written advice incorporates several

features of spoken discourse such as the use of question forms and personal pronouns. This is in accordance with website guidelines, such as in the case of CancerHelp UK: the patient information website of Cancer Research UK. These guidelines have been established with the aim of making the relationship between the writer and reader more interactive and therefore advice offered more approachable, persuasive and user-friendly. As the choice to write adopting a more conversational style is common to several similar advice texts, so it can be regarded as a generic feature of written health advice websites.

A similar overlap of spoken and written features is also true of the experience data due to the fact that the original recordings of interviews have been transcribed and edited before appearing on the website. The editing process has sought to keep the transcript as close to the original as possible and in several cases it is possible to listen to audio recordings or watch the video as well as reading the transcript. However, there are interviews where the preference of the interviewee has meant that only the transcript exists. In these cases it could be argued that something in the delivery of the original text as spoken has been lost in transcription. A more detailed overview of the two types of data indicates that although the balance between written and spoken elements may differ, both sources operate using elements of both written and spoken discourse. In this respect it is possible to say that although the language channel through which the advice is delivered is written or graphic, the medium of language employed is both spoken and written as it contains features of both.

Advice	Graphic channel Written/Spoken medium
Experience	Spoken then graphic channel Spoken medium

In addition to this there are complexities in the comparison of data due to the different modes and their inherent features. For example, certain authentic features of spoken discourse such as online processing can lead to natural ambiguities on the part of the speaker and therefore inherent uncertainties for the analyst. Of particular relevance to this study is the argument that experience is represented differently in writing and speech (Halliday, 1989). More specifically, there may be a product and process based emphasis on how we represent our experience depending upon the channel of communication. This can be applied to the current data as the more written advice can be categorised as a product presented to the reader whereas the spoken interviews are more related to a process conducted by the interviewer and interviewee. Halliday argues that that both forms represent...

> '...reality as being like itself. A piece of writing is an object; so what is represented by written language is also given the form of an object... But when you talk, you are doing, so when you represent by talking you say that something has happened or something was done.' (Halliday, 1989, p81).

This suggests that the written product based representation of reality involves more nouns and nominal groups and fewer processes whereas the converse would be true of the spoken process based representation. This assertion can only be assessed by closer examination of the patient advice and interviews but it is worth noting that Halliday also acknowledges that the 'distinction between speech and writing is becoming blurred as a result of modern technology' (Halliday, 1989, p81). Therefore this distinction may not be as straightforward in relation to website advice and interviews.

Although there were found to be differences in production and delivery, the impact upon transitivity patterns which emerged from the data can nevertheless be said to demonstrate the choices of those particular writers or speakers to represent an experience of terminal illness. The fact that this is presented in terms of professional advice or personal narrative can be seen as two points of view on the same general experience. Whether or not these two representations differ or

accord will hopefully become more apparent when comparing the results of the transitivity analysis.

Fortunately the topic areas and relevant interview responses which have been selected can be mapped on to the topic areas of the advice texts. However, it should be emphasised that this may owe more to design than coincidence in that decisions were consciously made by the Dipex team as to what should be extracted from the full interviews for inclusion in the website. This in itself is of interest in that decisions had to be made on priority topic areas and it is worth exploring the basis upon which these decisions were made.

There are further considerations regarding the range and selection of data at source. This was largely determined by Dipex's interview process which required interviewers to identify issues in advance for the interviews. In order to do this, interviewers carried out pre-interview reading on the relevant research background and recent research into the particular context of health they would be interviewing patients about. To some extent the topics and questions for later interviews were also determined by what had emerged from those conducted previously on the same context of health. Nevertheless, it is fair to assert that Dipex interviewers had planned the broad content areas of the interviews in advance.

In addition to this, selected extracts were then chosen from the original full interviews for inclusion on the website. However, the approach of Dipex was one of choosing what to include rather than what to exclude from the website and although the difference in emphasis may seem purely theoretical, the rationale behind their editorial choices and practices is based on good practice (Coyne, 1997). It can be broadly summarised as trying to ensure that within a given context of illness a full range of treatments, viewpoints and patient types were represented and available on the website. This was monitored by a 'specialist advisory panel' consisting of 'patients, health professionals and researchers'[1].

A further point of note relates to the length of interviews which range in duration from 30 seconds to 23 minutes. This was determined either by the outcome of the interviews or the editing process of Dipex. It was largely beyond the control of the current study and not felt to be grounds on which to discount the data. The fact that texts of unequal length were being compared could have had consequences for comparability of data. However, in response to this it is hoped that a balance has been achieved by working on the basis of percentages rather than totals. There was also an attempt to cross-reference topic areas, genders and age groups so that general tendencies could be drawn out rather than focusing exclusively on individual interviewees, although these individuals will form a significant area of research when exploring templates and rogue profiles, that is any particular instances where there appears to be deviation from the general patterns of participation as established by the data overall.

However, the fact remains that within longer interviews there is naturally a greater likelihood of certain processes occurring and for this reason a variety of approaches were taken to the data overall in order to address this potential imbalance. Therefore a three-pronged approach to the data has been established by analysing results firstly in terms of individual interviews. This was then followed by cross-referencing across general categories within all interviews such as gender, age or length of time living with diagnosis. Finally general categories according to topic areas such as 'receiving your diagnosis' or 'telling your children' were also examined and compared. This was carried out in order to examine transitivity patterns beyond the level of individual interviews and thus explore any emerging patterns at broader levels of situations such as 'telling your children' outlined in the final phase of cross referencing.

One interview was discounted on the grounds that although the interviewer directed their questions to the interviewee, it was the interviewee's wife (also present) who provided the bulk of the answers. In this instance it was felt that although the speaker may have been acting out of habit or kindness and simply

voicing what her husband may have already told her or had difficulty talking about, her response could not be taken in lieu of the patient's.

3.4.2 Practicalities of the Analysis

In addition to and in light of some of the methodological considerations outlined above, it is necessary to clarify some of the practical steps taken within the analytical process. The first of these was to establish what exactly was to be analysed within the data and what or who would constitute the focus of interest. The key entity with which this study is concerned is that of the patient but this cannot be at the expense of all other parties involved in the data. In fact it is only truly possible to measure the experience of the patient if they are considered in contrast to and interacting with other entities or agents such as doctors, nurses and close contacts such as family members. Thus there are three core human entities which are of interest to the transitivity analysis and these are defined as follows:

Doctor = doctors, nurses, medical experts

Patient = general patients - those being advised and specific patients - the interviewee

Other = family members, close friends, members of non-specialist support network

Other Support = support groups

However, it should perhaps be mentioned at this point that the above approach does not account for the distinction between real patients, as in the interview data, in contrast with fictional patients, as found in the advice data. In order to address this within the following chapters these two distinct types of patient will be referred to as the 'Advice Patient' and the 'Interview Patient' accordingly. A further consideration is that the analytical process and research method has required the compilation of two separate data sets of multiple advice and interview texts

respectively. This along with transitivity concordances has led to the merging of individual patients into one generalised and broadly 'typical' patient for each data set which emerges from the 'transitivity role-to-entity' profile based on the combined patients of each set of texts. Owing to the nature of this more generalised treatment of the patients within each text, it can certainly be argued that some of the more detailed distinctions between individual patients may well have been lost. However, because the current study is concerned with grammatical patterns at the higher frequency end of the scale, it is hoped that this will help to establish the more salient participant roles taken by patients overall.

Accordingly, only processes in which these entities are involved have been analysed. This leads on to the system of labelling which was employed in the analysis. In the first instance processes involving any of the four entities mentioned above were analysed for process types and colour coded according to one of the six broad process types: material, mental, relational, verbal, behavioural and existential. Totals were then calculated in terms of the distribution of process types within each interview and overall calculations for individual interview or groups were completed.

As outlined previously, the basic unit of analysis was taken at the process or clause level. The example below demonstrates how this was carried out and how different clauses and processes were handled. This example includes both a verbal and a mental process in which the patient is involved. At the first level, patient appears as the Sayer with their doctor as the Receiver. However, embedded within the patient's message (verbiage) is a further clause containing a mental process. Within this process the patient is the Senser who anticipates a number of years of life expectancy. In terms of the current study both processes and clauses are connected but distinctly different in transitivity terms and for this reason are accounted for separately and included within two process types and participant roles for the patient.

I haven't asked them specifically		how many years verbiage	I could expect...
Sayer	**Receiver**	**Phenomenon**	**Senser**

At this stage the totals and overviews were a necessary but very general foundation for the later analysis. The following phase of analysis required the labelling of participant roles according to the transitivity system outlined earlier. These participant roles were also colour coded according to entity so it was possible to see at a glance how much of the data involved each entity: Doctor, Patient and Other. In addition it was possible to identify which participant roles each entity occupied within the processes which they participated in. Fully analysed and coded sample texts from both data sets can be found in the Appendices B and C in order to demonstrate this phase of the analysis.

This then made it possible to calculate how often Patient appeared within a given participant role. For example, the Patient's appearance in the role of Actor could be calculated as a percentage of their overall participation in all roles. In this way it was possible for a profile to be built up based upon Patient's participation within processes. These profiles were compiled on a large scale to accommodate both sets of data thus providing a very broad profile of Patient's participation in both data sets. It should be emphasised that the participation of Patient is the prime concern of this study. However, other entities such as Doctor were considered where they appeared in connection with Patient, participating in the same transitivity process.

Entity profiles are useful for revealing how a particular entity participates overall and how often they take a particular participant role. Another way in which they were of use in this study was that they were used to assist in the measuring of dynamism or control afforded to a particular entity. Dynamism was calculated using a method of weighted scoring for each participant role and then multiplying this by the number of occurrences of a particular entity occupying that particular role. The

table below shows how the cline of dynamism has been modified to incorporate the following weighting system (Thompson, 2006).

Table 1: Dynamism Weighting

Dynamic	**Weighting**
↑ Assigner / Initiator	**+ 3**
Actor + Goal	**+ 2**
Actor – Goal and/or + Scope	**+ 1**
Behaver	**+ 1**
Sayer	**+ 1**
Senser	**+ 1**
Token	**0**
Carrier	**0**
Beneficiary	**- 1**
Phenomenon	**- 1**
Scope	**- 1**
↓ Goal	**- 2**
Passive	

These scores were then applied to specific processes extracted from the data in which Patient participates. This is demonstrated below using sample processes from the cline of dynamism.

Table 2: Dynamism Weighting with Examples

Role	Example	Score
Assigner /Initiator	...the thought of a life hereafter makes me shudder to be honest.	+3
Actor (+ animate Goal) Actor (+ inanimate Goal)	I will...push them (the doctors). I write down a list of questions and points	+2
Actor (– Goal or + Scope) Behaver Sayer + Receiver Sayer + Target Sayer Senser Senser + Phenomenon	...to make sure I didn't overdose... ...until I woke up in the Intensive Care Unit Well I haven't asked them specifically how many years... ...my eldest daughter and wife would discuss my treatment... ...when I say it doesn't bother me... I don't know (regarding euthanasia)... Somebody (this mentor) who knows about all the contacts...	+1
Token / Value Carrier	...whether it's my GP or a consultant that I've seen... ... both my wife and I had up to date wills in place.	0
Beneficiary Phenomenon (Complement) Scope	I could give myself a shot of morphine... I want my friends and family round me... ... when you're seeing a consultant...	-1
Goal/Target	... somebody wanting to get rid of their relatives...	- 2

Using the above framework it was possible to calculate the dynamism scoring for Doctor, Patient, Other and Illness and make comparisons between text types and individual texts.

So far the profiles outlined have only presented numerical information on the participation of each entity. However, this study is also interested in further detail on the participant roles within the context of their processes. In other words, a central focus within this study is their nature as well as their number. For example,

what the doctor is saying or what a patient is thinking are of as much importance as how often they say or think these things. Therefore, an additional approach to the data was necessary in order to provide more qualitative information about the linguistic patterns.

This approach required the categorisation and compilation of each transitivity process analysed within the data. Firstly the processes in individual text were categorised according to the involvement of each entity: Doctor, Patient, Other and Illness. Processes were then categorised further according to participant roles such as Actor, Carrier, Sayer or Goal. An example of a transitivity concordance for one of the Patient interviews can be found in Appendix A.

In the process of compiling the concordances a system of labelling was devised to allow for and signal the complexities of a transitivity analysis and the resultant concordance. The following extract from a concordance illustrates some of the labelling features.

Ref	**Patient as Actor + Goal**
18/19	...(them) putting their papers into tidy order...
19	...which I continually try to do (putting my papers into tidy order)...
25	... getting one's address list in order, that kind of thing...
26/27*	(It is) Much easier for me to do it than for them.
33/34#	...we've signed the documents...

The **'Ref'** column refers to the relevant line reference for a particular process and may be given as a single number or two numbers if the process appears on more than one line. In order to differentiate between different levels of analysis the numbers in bold were applied to the top level of analysis whilst non-bold numbers were used for all levels of analysis below the top level as in the following example where patient appears as Sayer on the top level of analysis but also Senser on the second level.

I haven't asked them specifically		how many years	I could expect...
Sayer	**Receiver**	verbiage	
		Phenomenon	Senser

Line numbers are also accompanied by the symbol * wherever there are two more participant roles involved. This can be seen in the penultimate example on the extract above whereby both the Patient 'I' and their doctor(s) 'them' appear in the same process. The asterisk indicates that the same process appears elsewhere in the concordance under either a different participant role or entity. The fact that the same process appeared more than once within the same concordance was not regarded as problematic since the participant roles involved were only included once.

The final example on the concordance demonstrates all of the above analytical considerations with the addition of a further feature it was felt necessary to account for. On some occasions the same participant role is shared by two or more entities.

Ref	**Patient as Actor + Goal**
33/34#	...we've signed the documents...

In the example above both the speaker and his wife have 'signed the documents' and are therefore both Actors in the same process. This occurrence is indicated by the symbol # in the line reference column and the same process would appear in the concordance under both 'Patient as Actor + Goal' and 'Other as Actor + Goal.

The above methods relate directly to several of the methodological considerations mentioned earlier when outlining the complexities of carrying out a transitivity analysis and are an attempt to address these complexities.

Compiling a detailed concordance in this way enabled the analyst to compare different entities in a number of different ways. The most accessible approach was to examine individual entities within a particular participant role. This focus was used to explore precise transitivity patterns on a level such as how the Patient as Senser participates.

Individual **Patient as Senser: cognitive** **desideration** **perception** **emotion** In an individual text

The next phase involved comparing these findings with how the same entity participates in other participant roles so that, for example, it was possible to compare the same Patient's participation in material processes as Actor, Goal or otherwise with their participation in mental processes.

Individual **Patient as Initiator** **Attributor** **Actor** **Behaver** **Sayer** **Senser** **Token/Value** **Carrier** **Beneficiary** **Phenomenon** **Scope** **Goal** **Circumstance** In an individual text

As well as considering the detailed participation of each entity individually, it was also necessary to compare each entity with each other in order to establish not only how the Patient is represented but also how they interact with Doctor, Other and

Illness within the same text. This was done by examining the concordance in the same manner as above but in relation to the overall participation of the Doctor, Other and Illness. By comparing all the individual entities within the same individual text, it was possible to see in detail what the Doctor, Patient, Other and Illness were doing in relation to each other in any given text.

It was also possible to compare the same entities across different individual texts combined. For example, when examining how different Patients represent their Illness, a transitivity concordance permitted an overall profile of the Patient's participation in the advice and interview data in the following way.

Patient as Initiator
Attributor
Actor
Behaver
Sayer
Senser
Token/Value
Carrier
Beneficiary
Phenomenon
Scope
Goal
Circumstance

In all texts

A broader approach to the concordance also involved examining the detailed participation of Patient across text types. In this case the data falls into two main classes: those of patient advice and patient experience interviews.

Patient as	Patient as
Initiator	Initiator
Attributor	Attributor
Actor	Actor
Behaver	Behaver
Sayer	Sayer
Senser	Senser
Token/Value	Token/Value
Carrier	Carrier
Beneficiary	Beneficiary
Phenomenon	Phenomenon
Scope	Scope
Goal	Goal
Circumstance	Circumstance
In all patient advice texts	**In all patient experience interviews**

Using the concordance in this way is not unlike the entity profile outlined earlier but where they dealt with the number of occurrences, a transitivity concordance provides a more detailed insight into what is occurring. Furthermore, a concordance can be revealing not only in terms of what appears in the text but also what does not appear. For this reason, each of the concordances also listed any participant roles which each entity did not participate in so that these observations could also be compared for patterns of absence.

However, one of the limitations of the transitivity concordance is that it treats each entity in isolation rather than in relation to the other entities involved in the same process. Whilst the appearance of another entity within the same clause often occurs and can be indicated within the labelling of the concordance, there is no built-in mechanism for identifying the precise interaction between one entity and another. This can be overcome by using the concordances collectively to establish a more general pattern of interaction between entities at the level of text type or genre. These general patterns are referred to as transitivity templates (McLaughin, 2002) and provide a formula of dominant process types within a particular text type

or genre. For example, a possible dominant template within the genre of medical information might be as follows:

ACTOR + **MATERIAL PROCESS** + **GOAL**
The Doctor acts on the Patient

In relation to the current data, it was possible to identify transitivity templates for both patient advice texts and patient experience interviews which will be described in more detail in the following chapter.

Chapter Four: Advice Data Results and Discussion

4.1 Patient Participation in Advice Texts

The following section will provide an overview of the key entity of advice Patient in terms of their overall involvement within all participant roles. The frequency with which these roles are taken will be considered within the advice data and this will lead to a more detailed examination of Patient's participation within specific high frequency participant roles so that, for example, the ways in which Patient appears as Actor can be considered. This will in turn make it possible to make comparisons between Patient in similar participant roles in both the advice and interview data. In addition, there will be some attention to the accompanying and emerging entities such as Doctor, Other, Illness, Treatment and Other Support so that their participation in relation to the key entity of Patient can be taken into account.

The results of the advice data are presented below containing totals for Patient in each participant role as a percentage of their overall participation. In the tables below, these appear firstly in order of dynamism as opposed to frequency, which will be presented separately in the following table. The roles indicated in bold denote a minimum participation of 1% and above.

Table 3a: Overall Participation of Patient in Participant Roles in Advice Data in Order of Dynamism

ROLE	No	%
Initiator	2	0.1
Attributor	10	0.7
Actor + animate goal	17	1.2
Actor + inanimate goal	150	10.6
Actor – goal/+ scope	279	19.65
Behaver	36	2.54
Sayer	181	12.75
Senser	216	15.21
Token	1	0.07
Value	0	0
Carrier	311	21.9
Beneficiary	27	1.9
Phenomenon	8	0.6
Scope	2	0.1
Goal	76	5.35
Receiver	26	1.83
Verbiage	0	0
Target	5	0.35
Attribute	5	0.35
Existent	0	0
Circumstance	68	4.8
Total	**1420**	**100**

Table 3b: Overall Participation of Patient in Participant Roles in Advice Data in Order of Frequency

ROLE	No	%
Carrier	311	21.9
Actor – goal or + scope	279	19.65
Senser	216	15.21
Sayer	181	12.75
Actor + inanimate goal	150	10.6
Goal	76	5.35
Circumstance	68	4.8
Behaver	36	2.54
Beneficiary	27	1.9
Receiver	26	1.83
Actor + animate goal	17	1.2
Attributor	10	0.7
Phenomenon	8	0.6
Target	5	0.35
Attribute	5	0.35
Initiator	2	0.1
Scope	2	0.1
Token	1	0.07
Total	**1420**	**100**

Following on from this, participant roles for Patient from the most frequent to those of lower frequency will be considered in order to establish whether and which patterns might emerge in the grammatical representations of Patient in the advice data. Only Participant roles which appear with high or reasonable frequency will be considered in detail in order to identify patterns and make comparisons later with the interview data.

4.2 Patient as Carrier

The following section will consider in more detail the participation of Patient as Carrier and the predominant attributes in the advice data. The role of Carrier occupies the highest position in terms of Patient's overall participation in almost 22% of all the processes in which Patient appears. Given the significance of this participant role for the Patient, it is may be of some value to analyse and discuss the ways in which Patient participates as Carrier and the main attributes which are ascribed to them in the advice data. In addition to being the most frequent Participant Role for Patient, this group is of interest because attributes are 'ascribed' and not 'given' and are indicative of the choices made by the writers. They are not determined by what is actually happening in the way that other process types such as material, verbal, mental and behavioural to some extent are. In contrast, they are determined by what we ascribe to 'objects' and how we perceive them and their qualities. In this respect, relational processes can reveal a great deal about the writers' view of Patient.

As outlined previously in the methodology section, relational processes can be broken down into processes of being or having, are generally related to states rather than actions and are used to describe things in terms of their qualities and identity. There are two types of relational process, known as attributive and identifying, concerned with describing the qualities of a particular person, place or thing or identifying one thing in relation to another. Of the two types, there is a tendency towards far more instances of attributive relational processes than identifying in general in the current data and this pattern is further pronounced in the case of Patient in that all the examples found are attributive processes. Furthermore, attributive relational processes can be subdivided into three main subtypes according to the type of attribute. These are 'intensive' which describe qualities, 'circumstantial' which describe location time, quantity and matter, and finally 'possessive' which describe ownership and belonging. Examples from each of the advice data can be found below.

Table 4: Types of Attributes and Distribution across Advice Data

Type	Describing	Example	No	%
Intensive	qualities	you are **positive**	219	71
Possessive	ownership and belonging	you have **a serious illness**	81	26
Circumstantial	location, time, quantity, matter	I had been **under the hospital** for 18 months	11	3
Total			**311**	**100**

The main type of attribute for Patient emerges as Intensive, accounting for over 70% of attributive processes in the advice data. These can be categorised further according to the type of qualities ascribed to Patient and the key types for Patient are shown below.

4.2.1 Intensive Attributes

Table 5: Types of Intensive Attributes and Distribution across Advice Data

Type	Example	No	% age
States with mental overtones	many people are **worried** about their treatment	78	36
General States	you can still be **independent** in other ways.	67	30
Health states	you feel **well** enough	62	29
Personal qualities	being **cheerful** and **optimistic**	12	5
Total		**219**	**100**

States with Mental Overtones

Of the four key types of intensive attributes for Patient, the most significant group is that of 'states with mental overtones'. These include examples such as 'they may feel shocked' and 'you may be confused, upset and worried'. These processes have mental overtones because states such as being shocked, confused, upset and worried have an underlying mental aspect. They could often have been expressed via a mental process but have instead been expressed as relational. For example, 'You may be confused, upset and worried' are all intensive attributes with mental

overtones which could also have been expressed as 'It confused, upset and worried me' or 'I worry'. The relational-mental overlap is also made evident by the fact that all of the attributes with mental overtones in the advice data can be mapped on to a specific type of mental process, as in the following examples.

Table 6: Patient's Intensive Attributes with Mental Overtones in Advice Data

Type	Example	No	%
Emotion	you seem to be feeling more down than ever	67	86
Cognition	you may become confused	11	14
Total		**78**	**100**

Emotion based States

As can be seen above, the vast majority of intensive attributes with mental overtones can be connected with mental processes of emotion which are overviewed below in order of frequency. These can also be grouped together in terms of semantic groups so that by combining attributes such as fear, afraid and frightened, a more consolidated and precise overview of Patient's attributes with mental overtones may be possible.

Table 7: Patient's Intensive Attributes with Mental Overtones - Emotion

Attribute	Number		%	
Worried	6	9	9	13.5
Concerned	2		3	
Nervous	1		1.5	
Frightened	4	7	6	10.5
Afraid	2		3	
Fear	1		1.5	
Angry	6	7	9	10.5
Anger	1		1.5	
Depressed	5	6	7.5	9
Depression	1		1.5	
Sad	5	6	7.5	9
Sadness	1		1.5	
Upset	5		7.5	
Cross	2	4	3	6
Bad tempered	1		1.5	
Irritable	1		1.5	
Shocked	3		4.25	
Numb	2	3	4.25	
Unable to feel any emotion	1			
Better	2		3	
Down	1	2	1.5	3
Low	1		1.5	
Isolated	1		1.5	
Tearful	1		1.5	
Overwhelmed	1		1.5	
Grief	1		1.5	
Worse	1		1.5	
Distressed	1		1.5	
Guilty	1		1.5	
as though the situation is happening to someone else...	1		1.5	
Relieved	1		1.5	
Happy	1		1.5	
Sane	1		1.5	
Good	1		1.5	
Confident	1		1.5	
Total	**67**		**100**	

To provide more detail on the key attributes above, it would seem that the predominant emotions can be classified as negative, with far fewer examples of positive attributes of emotion. The more negative attributes range from being worried, afraid and angry to depressed, sad and upset and these account for just under 90% of the group. This contrasts with attributes at the more positive end of the spectrum such as being or feeling better, relieved, happy, sane, good and confident.

Regarding the predominant and negative attributes with emotional overtones, a number of patterns emerge which represent Patient with certain emotional attributes that can be connected to certain key aspects of their experience and relationships. To some extent these can be regarded as originators or the bases of particular attributes because were it not for their presence, Patient might well not feel as they do. For example, Patient is worried about their cancer, pain, symptoms, treatment, whether treatment will work and whether it will be unpleasant. Although it could be argued that without these, other reasons to be worried may well exist for a patient, the fact remains that these provide the grounds for Patient being worried as stipulated in the text. The main triggers regarding frequent attributes with mental overtones of emotion are outlined below.

Attribute	Key triggers
Worried Concerned Nervous	cancer, pain, symptoms, treatment, whether treatment will work, whether treatment will be unpleasant, how you'll be cared for, the impact of diagnosis upon relationships, about going back to work

Attribute	Key triggers
Frightened Afraid Fear	about how you'll die, to ask doctor to repeat things you don't understand, people will think I could no longer do as good a job as I used to

Attribute	Key triggers
Angry Anger	towards those closest to you, towards doctors and nurses, towards God, with your illness, well people

Attribute	Key triggers
Depressed Depression	the diagnosis, treatment, the stress of my cancer

Attribute	Key triggers
Sad Sadness	illness

A number of issues can be identified within the above overview. Firstly, that illness, symptoms, treatment and care provide the main trigger for these attributes, such as 'you are very worried about your cancer' and 'you may be worried about pain or other symptoms'. Beyond illness, people and relationships are also a significant

trigger, as in 'you feel angry with those who are closest to you'. A final key trigger in this set is related to work and the feelings which are generated by returning to work or being able to work. Examples of this are 'I was nervous about going back to work' or 'I was afraid that they would think I was no longer able to do as good a job as I used to'.

To summarise, illness and treatment emerge, not surprisingly, as the most significant triggers for states with mental overtones of an emotional nature, with further factors such as people and work also evident triggers. These non-medical contexts are reminders of Patient as a person who has relationships with other people or a person who works, rather than solely a person with an illness who is under treatment. However, it should be noted that these contexts are invariably linked to illness, as in 'Others may be concerned about the impact a diagnosis of cancer may have on their relationships'.

Finally, according to the advice data, emotion based states for Patient are more likely to involve negative emotion states. This is a feature of emotion which might have been predicted based on the literature (Grumann and Spiegel, 2003; Johnston, 2004c; de Faye et al., 2006; Tamura et al., 2006a, 2006b; Lloyd-Williams et al., 2007) in which depression, anxiety, fear and emotional pain have been found to be a significant part of Patient experience of terminal illness. Such an aspect of Patient experience may have been anticipated within mental processes of emotion and yet appears to be often encoded as a relational process with mental overtones of emotion. It also indicates that in the advice data, Patient's negative emotions are more likely to be encoded as an attribute of them, rather than something which they feel.

Where the emotion based state is positive, typical triggers for this often appear as separate processes or as an Attributor. Typical examples are 'you feel better if you know why something has happened' and 'work helps people feel good about themselves', with typical triggers given below.

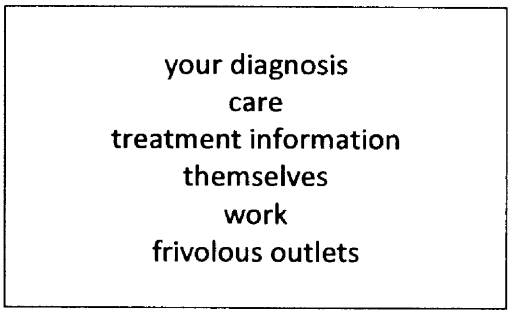


Fig. 13 Typical Triggers for Patient's positive emotion based states

Cognition based States

Patient states with overtones of cognition is a much smaller set and accounts for less than 15% of states with mental overtones. Within this set, the mental attributes are usually related to knowledge, awareness and beliefs and the key states are overviewed below.

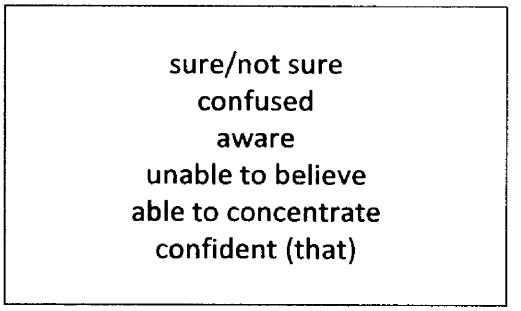


Fig. 14 Patient's Typical cognition based states

In some cases, there is no further information as to the basis of this state, as in 'you may become confused', whereby it is unclear where the confusion originates from. However, in many cases, a basis for the cognitive attribute is apparent and relates to a number of key states and contexts highlighted below. Overall, this also shows a transition from cognitive capacity to cognitive dissonance, moving from things which Patient is sure about to those where they are unsure and incredulous.

Attribute	Context
Sure	that you are saying the same things as you did before that the child understands the situation is not their fault
Aware	that they are there of what is known as 'magical thinking'
Confident	that you'll be cared for in the way that you wish
Not sure	whether things that you experience are real or not
Unable to believe	what is happening

Fig. 15 Patient's Typical cognition based states: capacity to dissonance

Alternatively, the context of this transition can be viewed from a more chronological perspective which relates to Patient cognitive states from diagnosis to death. This approach shows that the shift from cognitive capacity to dissonance is not necessarily a linear or progressive transition but possibly more dependent upon the context with a more cyclical pattern.

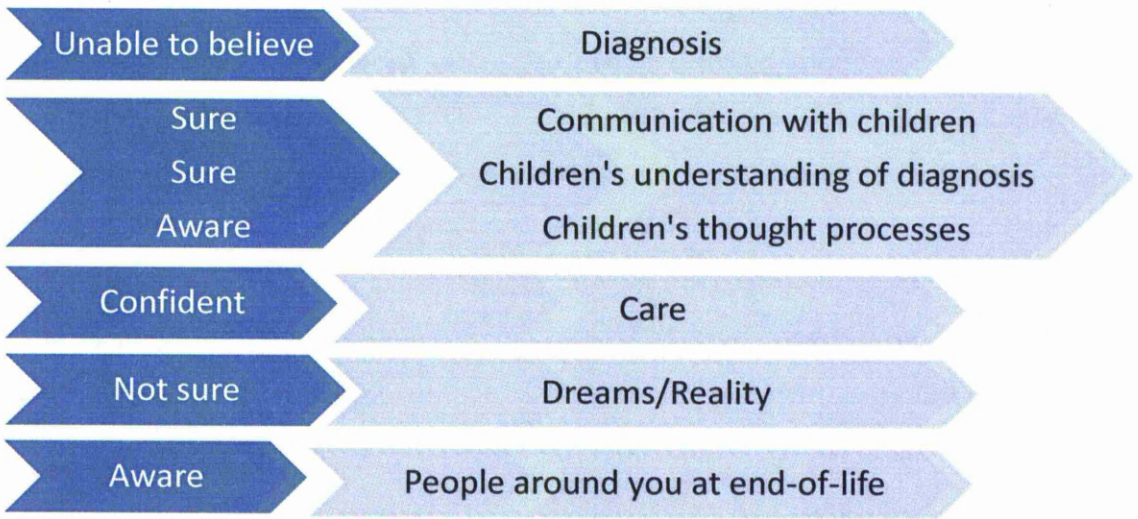


Fig. 16 Patient's Path of Cognitive capacity and dissonance States

This leads on to an overall comparison between states with mental overtones and their corresponding mental process in order to establish possible similarities and

differences between the two. An overview of the two types of related processes can be found below.

Table 8: Comparison of States with Mental Overtones and Mental Processes

States with Mental overtones	%	Mental processes	%
Emotion	84	Emotion	13
Cognition	14	Cognition	54
Desideration	0	Desideration	26
Perception	0	Perception	7

Clearly, there are significant differences between the two related process types, notably the reversal of emotion and cognition and the presence or absence of desideration and perception. In states with mental overtones, emotion states dominate whereas in mental process, emotion related processes are comparatively low. Furthermore, when considering positive and negative emotions in both process types there is a general positive-to-negative ratio reversal in that mental process of emotion in which Patient is Senser tend to be more positive than negative, where the reverse is true of states with mental overtones of emotion in which Patient is Carrier. In terms of Patient as Senser, they are more likely to 'love' than to 'fear' and as if compared with relational processes, are more likely to take the role of Carrier and 'be worried' and to 'feel afraid' than to take the related role of Senser and 'to worry' and 'to fear'. It could also be argued that the inclusion of more negative states of emotion, such as depression, within relational processes redresses the balance of expectation that these might appear in mental processes of emotion. The percentages for each are shown below.

Table 9: Positive and Negative Emotion in States and Processes

	States with mental overtones of emotion Patient as Carrier	Mental processes of emotion Patient as Senser
Positive	10.5%	66%
Negative	89.5%	34%

There is a further frequency reversal regarding cognitive states and processes, with cognition being less likely within relational attributive states than mental processes. In the advice data this indicates that, for example, Patient is less likely to 'be confused' than 'to understand'.

There is further divergence with respect to states with overtones of desideration and perception in that there are no examples of either in relational processes, in contrast to a clear focus within the data amongst mental processes. This may be partly due to the fact that fewer options exist in the language by which to express desideration and perception via relational attributes. What can be seen from the advice data is that Patient is more likely to express their preferences in mental processes than as emotional attributes and that patients' increased role within decision-making as indicated in the literature (Townshend, 1990; Roberts, 1999; Wilkinson et al., 1999; Jansen et al., 2001; Department of Health, 2003; Tong et al., 2003; Ache and Wallace, 2009; Grande and Ewing, 2009; Daveson et al., 2011), is not evident within this group of relational processes.

A number of further final observations can be summarised on states with mental overtones. Most examples are emotion based, demonstrating 'an alternative construal of emotion' (Halliday and Matthiessen, 1999, p143), with some cognition, and no perception or desideration based states. Regarding emotion based states, the majority of states are negative, triggered by illness. In addition, the more frequent states for Patient of 'anger' and 'depression' coincide with two key stages of grief as outlined by Kübler-Ross in her work on death and dying (1973) but do not include other stages such as 'bargaining' and 'acceptance'.

Finally, the choice of the writers to encode mental responses as relational attributive processes rather than mental processes presents Patient in the less dynamic role of Carrier of mental states rather than the more dynamic role of Senser in a mental process. To some extent, the use of relational processes to encode mental attributes emerges as a common feature of the advice data which appears to sidestep mental processes, particularly processes of emotion. This may be an unmarked choice or simply a more conventional way of encoding emotions which represents Patient as a less explicitly 'emotional' entity. On the other hand, it be suggested to have almost the reverse effect and that by blurring mental activity with another process type and the domain of attribution, this can represent Patient 'emotionally' in more than one process type and lead to an increase in Patient's participation in an emotional capacity.

General States

In addition to states with mental overtones, a number of other attributes are ascribed to Patient in the advice data. The following set relates to states which can be defined as general, rather than with mental overtones or specific health states, and account for 30% of Patient's intensive attributes. These attributes can be categorised in broad terms of positive, negative or neutral, although this in itself is not necessarily straightforward. For example, to 'have choices' might ordinarily be analysed as a positive attribute. However, in the context of the current data 'People with cancer face a lot of choices about the future' refers to treatment and end-of-life choices and the necessity to make those choices. This places a less than positive interpretation upon the choices and the process of facing them and in this context, the nature of the choices may present the opposite polarity as these choices include whether to try further treatment, where to die or whether to be buried or cremated. With close consideration to context, the positive, negative or neutral nature of these states can be summarised as follows:

Table 10: Positive and Negative States in Intensive Relational Processes

Type of State	Example	No	%
Positive	you can still be **independent** in other ways	24	37
Neutral	it may be helpful for you to be **present** when they are told	22	33
Negative	they may become **a burden**	20	30
Total		**66**	**100**

The group which can be categorised as positive cover a wide range of attributes which relate to being peaceful, adaptable, independent, communicative, close, good, keen, in control and involved. Examples include, 'you feel more able to talk to your children', 'you can still be independent in other ways' and 'you to feel more in control of your situation'. Furthermore, a range of contexts can be identified such as personal relationships, communication, difficult times, counselling, everyday life and end-of-life. No particular pattern emerges except that positive states are associated with a range of health-related contexts from Patient disclosing their diagnosis to their children to end-of-life stages. Beyond health-related contexts, positive states also appear in contexts such as everyday life and personal relationships, indicating that positive states are not only present in health-related contexts, but are also generated by and experienced in contexts other than those of health and illness. Where given, Attributors for such positive states are personal openness and physical activity.

Regarding neutral states, these relate to being alone, careful, present and accustomed to feelings. Examples include, 'it may be helpful for you to be present when they are told' and 'you want to be left alone'. Half of the examples in this set also relate to how Patient feels but appear as 'how you feel', 'what you feel' or 'the way you feel' and so without a specified adjective it is not possible to assign them to either positive or negative states. In this respect, it could be argued that the total number of neutral states has therefore been inflated. However, the fact remains that by not attaching specifically positive or negative attributes to Patient's states in these examples, the writers have chosen to represent these attributes as neutral.

This suggests a reluctance at times on the part of the writers to be overly prescriptive in relation to all states, although a clearer indication of how Patient feels emerges from states with mental overtones. The typical contexts for these general states are communication, everyday activity and being in company or alone.

The final set of general states relates to those which can be regarded as more negative. These include examples such as 'they may become a burden', 'people with cancer are poor insurance risks' and 'Some people are more prone to developing a cancer'. Similarly to positive states, a range of contexts can be identified such as before and after diagnosis, communication, the illness, living with cancer, work and end-of-life. A further feature of this set is that it contains states which might not be considered negative in another context, such as to 'face a lot of choices'.

When comparing positive and negative states, it is possible to see which contexts these occur within and where there is a degree of overlap or divergence, as shown below.

Positive	**Both**	**Negative**
personal relationships		before diagnosis
difficult times	communication	illness
counselling	end-of-life	living with cancer
everyday life		work

Fig. 17 Contexts of Positive and Negative States

Health states

Patient attributes which can be categorised as health states account for only slightly less than the previous category of general states, comprising 29% of intensive attributes. Within this category, health states are taken to refer to physical states. Although it is acknowledged that 'health' includes mental as well as physical health, examples of states related to mental health have been analysed within states with mental overtones. Typical examples of health states include, 'someone who is ill', 'Will I be in pain?' and 'If you feel well enough' and cover a range of states from gaining strength and physical improvement to terminal illness and physical deterioration. This set can be divided generally between positive and negative health states, accounting for 24% and 76% respectively.

Perhaps not surprisingly, health states are considerably more likely to be negative than positive for Patient. The most common negative health state relates to physical dependence or inability, as in 'being physically dependent on others' and 'they get less able to do things'. This is followed by Patient being 'ill' or 'terminally ill', as in 'Sometimes I will feel ill' and 'a close friend or relative who is terminally ill with cancer', representing Patient as being defined by their illness. Equally as common as illness is the state of 'weakness', found in 'people feel very weak' and 'they get weaker'. The next most common negative health state is that of being 'tired' or 'exhausted', which connects with the previous category of 'weakness'. A further type of health state is that of being 'in pain', followed by other isolated but not unrelated states of being or feeling 'sensitive' 'cold', 'old', 'slow', 'unconscious' and 'dead'. The overall combination of these attributes represents Patient in ill health and in a process of physical deterioration; or 'reduced role function' (Johnsen, et al., 2009, p496) ranging from losing ability and mobility to death, as shown below.

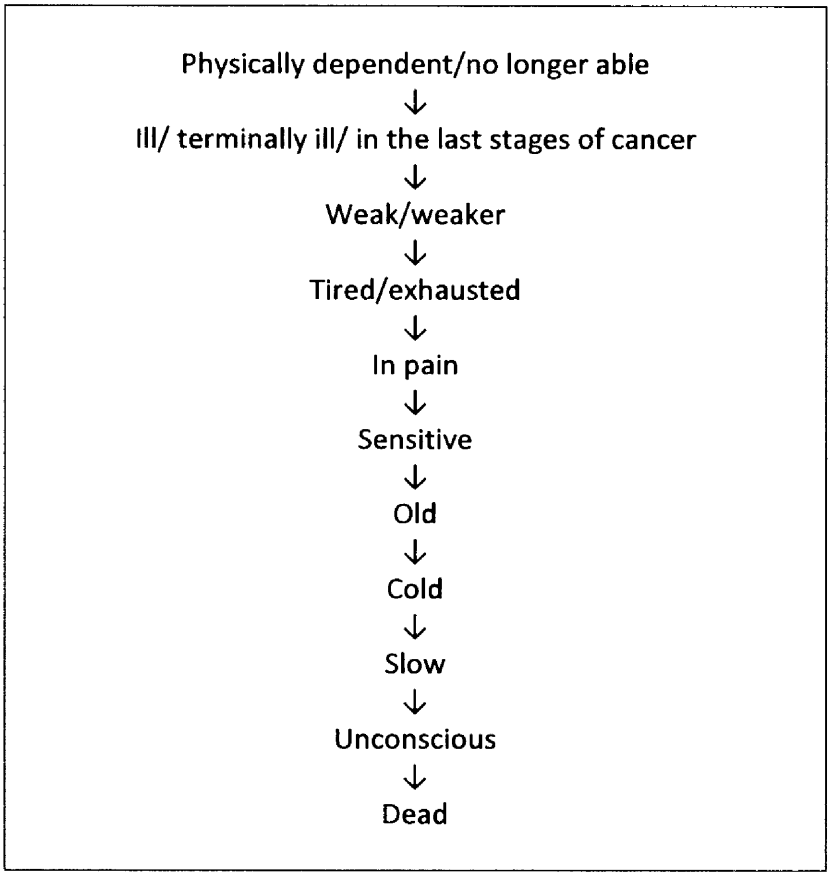


Fig. 18 The Path of Negative Health States

In contrast, more positive health states can be found in examples such as 'you feel well again' and 'you feel strong enough'. This set follows the opposite path of the negative health states, ranging from 'well' to 'cured', with Attributors being 'medicine', 'activity', and 'physical exercise'.

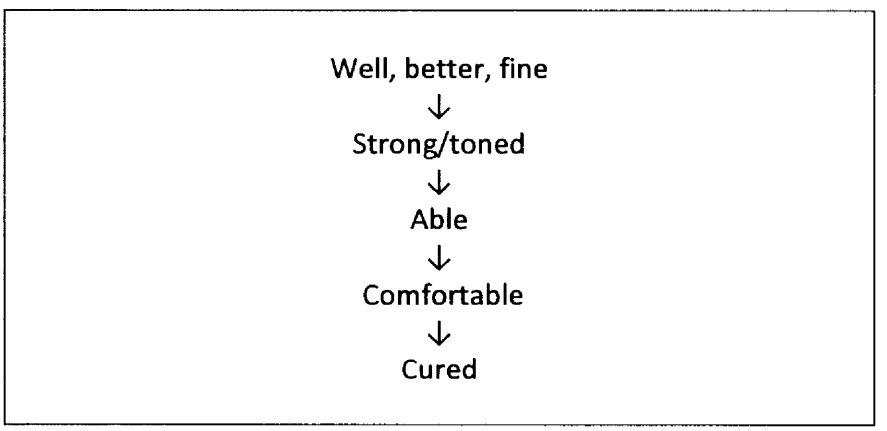


Fig. 19 The Path of Positive Health States

It is also of interest that these positive health states can be coupled with certain negative health states mentioned previously to form almost antonymous pairs, as indicated below.

Well, better, fine	Ill
↓	↓
Strong/toned	Weak
↓	↓
Able	No longer able
↓	↓
Comfortable	In pain
↓	↓
Cured	Dead

Fig. 20 Positive and Negative Health State Pairings

Personal Qualities

The next and final group of intensive attributes relates to personal qualities. Although this accounts for only 5% of intensive attributes, it offers some insight into the personal qualities of Patient, as ascribed by the writers of the advice texts. In terms of polarity, these qualities are overwhelmingly positive with Patient being described as 'positive' in over 40% of instances. Most of the remaining personal qualities are correspondingly positive, as in 'honest', 'cheerful' and 'optimistic'. Only one quality might be regarded as neutral, that being 'religious'. Finally, there is one example of a negative quality to be found in 'not cheerful'. However, the overall representation of Patient's personal qualities is one in which Patient appears as mostly positive in outlook, attitude and behaviour, with a glimpse of that positivity slipping only very rarely.

4.2.2 Possessive Attributes

Having considered intensive attributes for Patient which account for over 70% of overall attributes, the next key type of attribute to be considered is that of

possessive attributes. These are concerned with ownership and belonging, what Patient 'has' rather than what he/she 'is' or 'feels', and form 26% of Patient's relational attributive processes. The most evident type of attribute is 'cancer' or 'illness', which comprises one third of all of Patient's possessive attributes. The table below lists all attribute types in order of frequency, arranged according to groups of related attributes such as 'cancer' and 'symptoms' together to align associated attributes more closely.

Table 11: Associated Attributes in Possessive Relational Processes

Possessive Attributes	No	%	%
Cancer/illness	27	33	
Symptoms/side effects	6	7	40
Treatment	4	5	
Care/help/support	11	14	26
Advice/information	6	7	
Feelings	8	10	
Thoughts	2	3	16
Faith	2	3	
Money/things	5	6	
Time	4	5	
People	3	4	
Control	1	1	
Skills	1	1	
Energy	1	1	
	81	**100**	

As mentioned previously, the most common attribute which Patient possesses is their 'cancer', 'illness' or 'a serious illness', with the more specific illness-related attributes of side effects and symptoms such as 'you have no strength' and 'you have pain', accounting for 40% of this group. The frequency of such possessive attributes indicates that the advice data defines Patient primarily in terms of their

illness and symptoms. In view of these predominant attributes, Patient meets what can be described as certain 'role expectations' (Williams, 2004) by virtue of having an illness and symptoms. However, owing to the nature of their illness, Patient is unable to meet the second key part of that role expectation because as a terminal cancer patient, they are unable to get better. So whilst these attributes represent Patient within 'the sick role' (Armstrong, 1994), despite fulfilling the obligation of wanting to get better, Patient in this context of health may be unable to achieve that particular goal. The inability of Patient to bridge this gap is one of central importance to this study as is how the 'role expectations' placed upon them may vary from those placed upon Patients in other contexts of health, such as where recovery is a possibility.

Following on from this, over a quarter of Patient's possessive attributes relate to 'care, advice and treatment' which have been grouped together as attributes which are designed to be helpful and supportive for Patient. Examples include 'People may need quite a lot of physical help', 'as much help and advice as you need' and 'I need a different type of treatment'. Care related attributes are the largest component of this set, accounting for 14% of possessive attributes, with advice and information comprising 7%. In keeping with material processes, treatment is relatively infrequent and accounts for only 5% of this group. A particular feature of this group is that 64% of these possessive attributes appear in terms of what Patient 'needs' rather than what Patient 'has' and so in this respect can be regarded the writers' compilation of Patient's needs or as 'expected' rather than necessarily 'actual' attributes.

The next set includes attributes of 'feelings, thoughts and faith' and are related to Patient's internal attributes of feelings, thought and beliefs, such as 'some of the emotions that you have' and 'you may have thoughts which are like dreams'. These make up 16% of the total possessive attributes and there is a degree of overlap with mental processes and states with mental attributes in that these exist in the mind of the Patient, rather than the external world. In comparison with intensive states with mental overtones, these attributes are usually referred to generically as

'feelings' or 'emotions' rather than as a specific feeling such as 'love'. Although this is a feature of some states with mental overtones, the extent to which feelings have been generalised is far greater in this set. Examples of feelings which Patient has which are specified are positive or presented positively, such as 'they have a better appreciation of the ordinary things of life' and 'you have a faith'.

The remaining possessive attributes for Patient are less frequent and do not combine to form any obvious groups. The first relates to possessions such as money and belongings, as in 'your money and things you own'. Patient's possession of 'time' also appears, as in 'you have some time to yourself', 'you haven't had time to think' and 'you need time', which presents time as an attribute which Patient has, does not have and also needs. A further possessive attribute relates to 'people', such as 'Who would you like to have around you?' and 'you have children'. The final attributes appear once only and relate to 'control', 'skills' and 'energy'. The first attribute appears as something which Patient does not have, as in 'hardly something you have any control over'. This represents Patient as having an 'external locus of control' whereby 'they do not feel in control of events' (Banyard, 1996, p174); a representation which does not take into account findings which suggest the contrary in relation to illness, treatment and end-of-life choices (Lewis, 1989; Henselmans, 2010; Beaver and Booth, 2007). 'Skills' appear in terms of what Patient needs rather than possesses, whilst 'energy' appears as an attribute which Patient has as increase of under certain conditions, as in 'they have more energy when they take part in physical activities'. This contrasts with earlier examples of symptoms and negative health states involving fatigue and it should be emphasised that Patient only has increased energy after physical activities and this may not always be possible for Patients with advanced cancer.

A final approach to categorising these possessive attributes is according to whether they appear to be positive, negative or neutral attributes. These have been categorised as such where it was felt that the polarity was clear, such as 'cancer' and 'close friend or relative', with more ambiguous examples being allocated to the neutral group. The overall distribution of possessive attributes according to polarity

represents Patient with 43% positive attributes, 40% negative attributes and 17% neutral. Positive examples include 'help', 'support' 'time' and 'energy', whilst negative attributes include 'illness', 'pain', 'symptoms' and 'trouble' and it is of some interest that attributes of both types are almost equal in frequency with a slight incline towards more positive attributes. This represents Patient as achieving a relative balance between attributes of both types despite the fact that 65% of all the attributes in this group are directly or indirectly illness related.

4.2.3 Circumstantial Attributes

The final group of attributes pertain to those labelled circumstantial, related to location, time, quantity and matter. Examples from the advice data include 'I had been under the hospital for 18 months', 'you have never been in hospital', 'some people stay in their own homes' and 'you have to stay in bed'. In total these account for only 3% of all patient attributes and describe locations such as hospital, home or being in bed. In some cases other people share the same location and they are a key part of the circumstantial attribute, as in 'you are with the doctor'. Overall, a link can be made between the circumstantial location and context of health, particularly in relation to where Patient receives treatment or care.

In conclusion regarding relational processes, certain attributes may be predictable and the initial hypothesis was that the predominant attributes of Patient would be their illness and resultant symptoms. The extent to which these have emerged is that 31% of Patient attributes are directly related to illness and symptoms, as indicated below. Perhaps given that medical advice websites are primarily concerned with giving advice on medical matters such as symptoms, it is not surprising that this constitutes the leading type of attribute.

Table 12: Overview of Illness Related Patient Attributes

Type	No	% of Patient Attributes
Intensive - Health states	62	31
Possessive – cancer/ illness	27	
Symptoms/side effects	6	
Total	95	

In addition to the extent to which these predictable attributes appear, what is also of interest is which other types of attributes emerge. The two emerging attributes are states with mental overtones and general states. Within the former, the dominant mental overtones relate to emotions and these attributes tend towards negative emotions far more than positive. In total, states with mental overtones account for over 25% of Patient's total attributes. The cumulative effect of these relational processes with mental overtones in addition to mental processes is that there is greater focus upon Patient's feelings. In fact, if mental processes and relational processes with mental overtones are combined, this would form the second largest group within Patient's overall activity in the advice data. It accounts for 21% of Patient's total participation here and is greater in number than Patient as Senser in all types of mental processes. To be more specific regarding mental processes of emotion and attributes of an emotional nature, these account for 7% of Patient's total participation, significantly increasing Patient's participation in an emotional capacity. For this to be a chosen focal point within medical advice texts may not necessarily have been predicted and suggests a change in the scope of advice texts such as these which now aim to advise Patient beyond the purely medical facts, thereby widening the remit of advice to include emotional as well as medical matters.

General states account for 21% of Patient's total attributes and can be divided broadly equally between positive, negative and neutral states, with a slight incline towards positive. Although it was possible that other non-medical attributes might emerge such as children, other family members or hobbies, these have not appeared in significant numbers in the advice data.

Furthermore, there is evidence of relational processes being used in a way which is complementary to other process types within the data. For example, relational processes of attribution for Patient have revealed aspects of Patient experience such as pain, fatigue or depression which may have been anticipated within other process types such as mental or material. These aspects are certainly evident in the advice data but not necessarily within the process type which they may initially have been expected. Whilst they have not been overlooked, when they do appear, Patient is in the less dynamic role of Carrier as opposed to Senser or Actor.

Moreover, in representing Patient in transitivity slots of reduced dynamism, these examples indicate some compliance with more traditional representations of patients within medical texts whereby Patient is typically acted upon, spoken to and possesses an illness with symptoms. Evidently, this representation is not entirely absent from the current advice data but it is not the predominant representation of Patient which emerges. The overall representation of Patient in relational processes which unfolds in the advice data is more complex than the mere carrying of health states. Although the overview of possessive attributes in the advice data defines Patient primarily in terms of their illness and symptoms, a range of other types of relational processes broaden the representation of Patient beyond the traditional parameters of the biomedical model and the medical gaze, to include states with mental overtones, more general states and personal qualities. These serve to represent Patient in a way which has broken with the tradition of medical texts of the past, and represents Patient as a person beyond the illness.

A further key finding is that whilst Patient possesses the prerequisite qualities of the 'sick role' (Parsons, 1951; Armstrong, 1994), they are not in a position to fully

realise that role in terms of illness recovery and it may be this shortfall and the writers' recognition of it, which perhaps leads the increasing emphasis upon Patient's mental activity in the advice data. The possibility of a causal relation between the context of health of terminal illness and the accompanying representation of Patient's mental activity, particularly of an emotional nature, should not be discounted. In contrast to Patients in a non-terminal context of health, the 'role expectations' of recovery are not applicable to the Patient in the current data. However, it could be argued that the representations of mental activity places a unique set of emotion-related 'role expectations' upon the Patient with terminal illness.

Finally, the analysis of relational attributive processes suggests that these processes are not as straightforward as first imagined. They reveal Patient and their attributes to be of greater significance than the process of 'being' or 'having'. Moreover, the analytical outcome is not simply related to what Patient 'is' or 'has' but the overtones of and connections to other process types such as material or mental. They demonstrate the function of relational processes in bridging material and mental processes and experience; the convergence of Patient's 'outer experience' of the external world and 'inner experience' of the internal world of their own mind. They often reveal this overlap and how 'outer experience and this inner experience may be construed by 'relational' clauses; but they model this experience as 'being' rather than 'doing' or 'sensing' (Halliday and Matthiessen, 2004, p211).

4.3 Patient as Actor – Goal/+Scope

The second most frequent role for Patient is as Actor without a Goal or with Scope. This group accounts for almost 20% of Patient's overall participation within the advice data and there are certain subgroups within this larger group which have been categorised according to the nature of the activity engaged in. An overview of these can be found below. In terms of whether these processes are intentional or involuntary, the former category accounts for 80% of this group. In cases where processes are involuntary, in the vast majority these are processes connected with dying.

Table 13: Patient as Actor – Goal/+ Scope

Process Group	No	%
Living/Daily activities	60	21
Coping with	36	13
Adjusting	35	13
Living/New activities	33	12
Dying related	34	12
Dying	21	8
Having treatment	20	7
Researching	14	5
Prioritising/Achieving	11	4
End-of-life preparing	5	2
Reacting to illness	5	2
Communicating	3	1
Living/Surviving	2	1
Total	**279**	**100**

These are the key groups of processes in order of frequency. However, a clearer overview can be gained by combining certain groups which incline towards each other semantically. This is shown in the table below and provides a more cohesive overview of Patient as Actor, showing the three key areas of activity in this group in bold, related to living, coping and dying, with living and coping both being more prevalent than dying.

Table 14: Patient as Actor – Goal/+ Scope Resorted

Process Group	No	No	%	%
Living/Daily activities	60	**95**	21	**33**
Living/New activities	33		11	
Living/surviving	2		1	
Coping	36	**71**	13	**26**
Adjusting	35		13	
Dying	21	**55**	8	**20**
Dying related	34		12	
Having treatment	20	20	7	7
Researching	14	14	5	5
Prioritising/Achieving	11	11	4	4
End-of-life preparing	5	5	2	2
Reacting to illness	5	5	2	2
Communicating	3	3	1	1
Total	**279**	**279**	**100**	**100**

As the table shows, areas can be grouped together in general terms such as 'living' comprised of both 'everyday living and routine activities' and 'living life to the full and new activities'. Examples of the former include 'just trying to carry out ordinary daily activities' and to 'keep up with your daily routine' and simple everyday tasks such as 'getting up', 'washing' and 'dressing'. This group also includes actions which take place outside of the home such as 'returning to work' and 'going to work'. Together they conform to the pattern established in other material and mental processes and previous research in which the maintenance of daily routine provides a sense of control for Patient and helps them to create meaning via day-to-day activities (Armstrong-Coster, 2004; Kennedy and Lloyd-Williams, 2009b), which La Cour et al. refer to as 'routines and continuity as a platform for agency' (2009, p474). In turn, this sense of control may influence Patient's ability to cope with

their illness (Forshaw, 2002) because 'patients who can find a sense of meaning ... adjust well to their cancer' (WHO, 2002, p21).

However, it is also possible to divide these processes into actions which Patient can carry out with ease and those which they struggle with or are unable to carry out. Examples of this are 'I've always done the cooking', 'being helped to go to the toilet' and 'some people can't return to their jobs because of their cancer'. A breakdown of these processes viewed in this way is shown in table 15.

Table 15: Patient as Actor – Goal/+ Scope: Can Do → Cannot Do Overview

Nature of Activity	No	%
Can do	42	70
Struggles to do	11	18
Cannot do	7	12
Total	**60**	**100**

Overall this shows that Patient can do more of the activities than they struggle with or cannot do. Nevertheless, this also represents a sequence of events characterised by deterioration of Patient's active participation in certain everyday activities (Taylor and Currow, 2003). For instance, simple everyday activities such as 'getting up', 'washing' or 'getting dressed' are examples of actions which usually go unmentioned and yet are specifically highlighted in this section. This may possibly be because these actions now present more of a challenge than usual and have become part of 'living with cancer' where maintaining routine is important and Patient is advised 'to continue my normal activities' as far as possible. How far this can be reasonably expected can be summed up by the example from the data 'some people do manage to lead an almost normal life during their treatment'. Furthermore adjusting to day-to-day life, particularly after treatment, is an area in which patients have recommended greater support and more specific advice (National Cancer Alliance, 2001; 2002).

This suggests a general focus upon living as a key area of activity for Patient but with a division between life before; as usual and life now; with revisions. It could therefore be argued that daily activities form part of a crucial link between the two time frames and are instrumental in navigating the transition from life before and after the cancer diagnosis so that Patient can adapt to changes in their life now that they are living with cancer. To be more specific, studies have shown that 'by emphasizing routines the person with advanced cancer may experience a sense of hope, embedded in moments of activity repeatedly returning in daily life ... that through familiar activity such as cooking, the participants found ways to construct and embed new meanings in an activity they had pursued before their illness' (La Cour et al., 2009, p 477).

The other 'living' group, comprising 11% overall, relates to living life to the full and activities which may be entirely new to Patient or something which they have always wanted to do. Examples of this are 'people with cancer can live each day to the fullest' and 'new, fun things that they have never done before'. This group can be further divided between living life to the full in general or specific actions such as taking up hobbies, doing sport and travelling. The general subgroup accounts for 18% of this set whilst the greatest emphasis is upon the latter, more specific type of activity accounting for 82%. This suggests that there is a degree of emphasis in the data upon positive activity, designed to help Patient enjoy life and experience fun and engage in new activities, as well as reassurance from familiar activities.

One final set of 'living' related processes appears and refers to living in terms of survival, as in 'What percentage of patients with my type of tumor live five years or more?' In total these account for only 1% of Patient's activity related to 'living' and this indicates that there is far greater emphasis on living with cancer or living life to the full despite cancer than upon surviving cancer. The advice data therefore represents Patient as more likely to do something they have always wanted to do such as 'ride in a hot air balloon' than they might be to 'live five years or more'.

The second largest group of Patient's activity as Actor –Goal/+Scope refers to processes of coping and adjustment. This emerges as a significant area of material activity and forms 26% of this group. They can be equally divided between coping and adjusting with examples of each being 'me and my family deal with the disease' and 'adjusting to life after cancer treatment'. The first subgroup offers advice on coping in the general sense rather than any specific coping strategies and this is reflected in the nature of the processes, shown below. In the majority of examples, there is a uniformity of process in that 'cope with' or 'deal with' make up almost 80% of the examples in this subgroup.

Table 16a: Patient as Actor – Goal/+ Scope in 'Coping' Processes

Material Process	**No**	**%**
Cope with	20	56
Deal with	8	22
Manage etc	8	22
Total	**36**	**100**

Table 16b: Patient as Actor – Goal/+ Scope in 'Coping' Processes

Scope	**No**	**%**
Illness	20	56
Life/experience etc	7	19
Emotions	6	17
Treatment	3	8
Total	**36**	**100**

Where Scope appears in these processes, there are four key contexts for Patient 'coping', as shown in the table above. Perhaps unsurprisingly, the most significant area of coping, accounting for over 50%, relates to 'illness', as in 'you cope better with the illness'. Here, 'illness' is being treated as Scope rather than circumstance because 'deal with' or 'cope with' have been analysed as prepositional phrasal verbs, not be used without 'with' and followed by 'something' which is being 'coped

with'. In terms of coping with illness, there is believed to be a correlation between the employment of coping strategies and the level of threat presented by the illness (Kelly, 2004) and given that terminal illness presents a significantly high level of threat, it might be expected that Patient will employ various coping strategies and that these processes would be evident in the data. It has also been argued that illness presents a particular and fundamental challenge for the patient whereby diagnosing an illness creates a 'new 'master' identity for the patient' to cope with and adapt to (Armstrong, 1994, p69). As Killeen claims in her reflections on cancer and personhood, 'just as good health means everything to a person, illness alters the life of the entire individual' (2004, p203). This will be explored further when considering relational processes and Patient self-definition.

Illness as Scope is followed by the more general group of 'life, experience and your situation' and conforms to the rather generalised nature of the advice being given. Examples of this are 'you can begin to cope with life again' and 'someone who has been through the same experience'. Compared to 'illness' as Scope, this group is characterised by the more general nature of the Scope involved and although there is some variation within the group, it can be argued that they are all influenced by and connected to 'illness'. Patient's life is now one in which 'living with terminal illness' is an essential feature and their experience and situation both refer to 'living with terminal illness'. In this respect, it can be claimed that illness forms a common thread running through the problems which Patient has to cope with (Armstrong-Coster, 2004), as shown by the type of Scope involved in material processes of coping.

Emotions and feelings form the third Scope group and although there may be an overlap with mental processes of emotion, in the case of the process 'to cope' in this group, it is unclear as to whether this involves purely mental activity or mental and material activity. For example, 'to accept your situation' can be categorised as a mental process of emotion, whereas 'to cope with your emotions' may require practical material activity in addition to mental activity. In addition, 'coping' has been defined as 'cognitive and behavioural efforts to manage demands that are

appraised as taxing an individual's resources' (deFaye et al., 2006, p240). Owing to this overlap, processes of coping and managing have been ascribed to the material category unless clearly indicated as purely mental activity.

These processes also include examples which indicate difficulty in coping such as 'the emotions and feelings do not get easier to deal with' and 'these emotions can be frightening and difficult to deal with' and introduce an element of Patient coping, but not with ease. Whilst these examples suggest that Patient is being represented as not necessarily coping comfortably, there are no examples in which Patient fails to cope with their emotions as found in medical and psychiatric studies (Chochinov et al., 1998; Weisman and Worden, 1986).

Finally, in 8% of this subgroup Patient is involved in coping with 'treatment', as in 'you are also coping with the treatment'. There are fewer examples of treatment in Patient's processes of coping, suggesting an assumption that treatment may be an area in which Patient is not necessarily expected to always cope. Alternatively, processes of coping may not be emphasised because Patient is expected to cope with treatment because, despite its side effects, it is for Patient's benefit. In fact, Patient is six times more likely to engage in more general material processes such as 'having treatment' than they are to 'cope with treatment'.

Similarly to processes of 'coping', those of 'adjusting' tend to be of a general nature, as in 'you can adjust to your situation' and 'you adjust to life after treatment'. They can be characterised as processes in which Patient adapts to living with cancer. However, there are also examples of more specific activities such as 'to set small achievable goals' and 'Do I need to take any special precautions at home?' in which Patient makes the necessary alterations to their home, lifestyle and approach to life in order to ensure greater quality of life. Such examples appear to recognise the relationship between 'patients' coping resources and quality of life' (Mårtensson et al., 2008, p350). They can also be seen as examples of adaptation and adjustment which Patient engages in and are regarded as 'processes of

adjusting to demands of living' and attempts to 'achieve the outcomes of coping efforts' (Somerfield et al., 1999, p 334).

The literature highlights several approaches to coping with and adapting to illness such as denial, avoidance and resignation (Kelly, 2004) and it is not necessarily coincidental that these can be seen to overlap with the first and last of five key stages in reacting to terminal illness; namely, denial, anger, bargaining, depression and acceptance (Kübler-Ross, 1973). Similarly, de Faye et al. (2006) identified categories of 'problem-focused' and 'emotion-focused' strategies to coping with advanced cancer. According to Bradley et al., coping 'has two major functions: dealing with the problem that is causing distress (problem-focused coping) and regulating emotion (emotion-focused coping)' (2010, p1211). Furthermore, the two approaches to coping have different aims or 'different targets of action. One is the offending situation; the other is our emotional state' (Lazarus and Lazarus, 2006, p58).

Whilst more recent literature suggests the need for a range of coping devices, this range is not apparent in the data owing to the very general nature of the advice on coping. De Faye et al (2006) highlight this as a weakness within psycho-oncology, suggesting that in some research into patient coping strategies, there has been a tendency towards an 'overly broad' approach (p236). This concurs with the findings in the advice data in that Patients are represented as coping with a number of things but not given advice on specific coping strategies. Therefore, it could be claimed that the advice does not take into account the breadth of specific strategies required to actually 'cope with' the illness and its associated challenges and so fails to adopt a sufficiently 'problem-specific' approach to coping with cancer (Somerfield et al, 1999). Nor does it fully take into consideration that a degree of flexibility is required regarding the application of coping strategies by different people to these challenges over a period of time (Brennan, 2001 and de Faye et al., 2006) and 'the fact that people with advanced cancer must cope concurrently with multiple problems across different dimensions of stress' (de Faye et al., 2006, p240).

De Faye et al. (2006) also divided the specific problems being coped with into physical, social and existential categories. Each of these is represented broadly within the advice data in terms of the type of Scope which Patient copes with, as shown in the examples below. The fact that all three types of problems can be found but the coping and adjustment processes remain rather general, would support the claim that despite the range of specific problems Patient has to cope with, there is a shortfall in specific and corresponding coping strategies (de Faye et al., 2006).

Type of Problem being coped with	Example of Equivalent in Scope
Physical	- coping with your illness - you are also coping with the side effects
Social	- treatment may affect how you relate to them
Existential	- you adjust to living with your diagnosis - you haven't been able to manage on your own

Fig. 21 Patient as Actor –Goal/+Scope: 'dimensions of stress' (adapted from de Faye et al., 2006)

After living and coping, the third group of material activity for Patient involves dying and this accounts for 20% of Patient's overall activity in material processes without Goal. The two main categories within this group relate to processes in which 'dying' is explicitly mentioned and secondly, those which can be regarded as 'dying related' activity. For example, 'you may die suddenly' differs from 'the person's body will relax completely' in that the former describes the process of dying, whereas the latter describes a process which appears as a possible part of the process of dying. The former 'dying' group is relatively easy to identify as it usually involves the verb 'to die'. Interestingly, the lexical choice of 'die' in this group also complies with advice given regarding verbal processes on the use of the word 'death' rather than euphemisms. This demonstrates that the writers are employing a similarly unambiguous and direct choice when advising Patient on this material process as they have advised Patient to employ when explaining the situation to other people. Examples include, 'you may die within the next few months' and 'how and where

you would like to die'. These also represent Patient in processes of dying characterised by 'resignation' (Kelly, 2004) and 'acceptance' (Kübler-Ross, 1973), which are thought to appear within the final stages of coping and adapting to terminal illness.

The second group includes a wider range of processes with the common theme of being related to death. When considered out of context, these processes may not immediately seem connected to dying but can be grouped together within this context because they describe actions which take place as part of the dying process. Further examples include, 'people move into a phase where their sleep becomes deeper', 'your muscles may waste away' and 'a person stops drinking'. These processes offer a more detailed description of the mechanics of dying and what Patient can expect to happen.

The table below shows that 'dying related' processes are more frequent than 'dying' itself. On first impressions, this might have been anticipated on the grounds of death being an uncomfortable topic and one which is more likely to be addressed and referred to euphemistically than directly. However, this does not appear to be the case in the current data. On the contrary, the presence of more 'death related' processes such as 'a person stops eating' serve to describe in more explicit detail some of the physical processes which accompany dying. Therefore, it cannot be argued that by using words other than 'die' or referring to other processes, the issue of death is being avoided. A more accurate explanation is that Patient is being advised on and prepared for what will happen in the final stages of life through the explicit description of the processes involved in dying. Patient's knowledge and understanding of the dying process has been stipulated as one of the principles of a good death (Johnston, 2004a) and it can be argued that such knowledge and understanding are an essential component of Kübler-Ross' 'acceptance' stage (1973).

Table 17: Patient as Actor – Goal/+ Scope in 'Dying' Processes

Process	No	%
Dying	21	38
Dying related	34	62
Total	**55**	**100**

A further defining feature is the emphasis upon activities which Patient can no longer do or their body will stop doing. For example, 'people are not able to get out of bed at all', represents Patient as no longer able to do something they once could and this represents the situation differently from simply 'they lie still'. Within the group of 'dying related' processes over 40% are concerned with actions which Patient can no longer do or their body has simply stopped doing such as 'you no longer fight'. This gives significant coverage to the loss of physical function which is likely to occur prior to dying, referred to as the 'gradual deterioration in functional status' (2003, p31). When compared to the key indicators specified by Ellershaw and Ward (2003) in the diagnosis of dying, similarities can be found with examples in the advice data. This suggest that just as health professionals are being trained in the identification of these key indicators to enable accurate and prompt diagnosis of dying, patients are also being trained and prepared as their awareness of these indicators is being increased.

Clinical Indicator	Example from advice data
The patient becomes bedbound	People are not able to get out of bed at all
The patient is semicomatose	They drift in and out of consciousness
The patient is able to take only sips of fluid	Once a person stops drinking
The patient is no longer able to take oral drugs	Once a person stops eating

Fig. 22 Key Indicators of the Dying Phase (adapted from Ellershaw and Ward 2003)

The next group relates to 'treatment' and accounts for 7% of Patient's participation in these material processes. Examples include 'the operation I had' and 'me ... receiving a different type of treatment'. As with mental processes, the quantity seems lower than anticipated and suggests that although the focus upon treatment may be more frequent in some process types such as verbal, it does not necessarily apply equally to other process types such as mental and in this case, material. In general, the processes involved in this group are generalised rather than medicalised but overall can be seen as covering a range of actions which form a chain of events in the treatment trajectory, as illustrated below. However, one limitation of this overview as presented below is that it presents treatment as a linear process when in truth it may be less linear and more cyclical at times, depending on the patient's individual trajectory.

Fig. 23 Patient as Actor –Goal/+Scope: the treatment trajectory

The remaining groups fall below 5% or less of Patient's participation in material processes -Goal/+Scope and so will be dealt with briefly. The first of these relates to research activity in which Patient is engaged in activities such as accessing sources of help, visiting websites and reading. Examples include, 'read more' and 'a number of sources of help you can turn to for practical advice, medical information, emotional support or spiritual comfort'. This group has some connection with other material research processes in which Patient acts upon information based Goals and related mental processes in which Patient learns about or understands their illness and treatment. In this group, there is also a certain emphasis upon website

navigation processes in particular, as in 'looking on the Internet' and 'you can choose from the menu below'. In this respect, Patient is represented as actively engaged not only in research, but specifically online research and presents a patient profile in which internet use is assumed.

The next group relates to prioritising and achieving in which Patient is engaged in 'working towards something' and 'what they want to achieve'. These can be seen as related to other material processes such as 'setting goals' and 'setting your priorities' and mental processes in which Patient thinks about and makes choices according to their priorities. Combined, they carry a common thread of considering priorities, planning and then acting upon both in order for Patient to achieve what is important to them. This represents Patient as acting in view of their revised priorities and living life according to these priorities. There is also some coverage of Patient's limitations in this area in examples such as 'you cannot meet other aims'.

The three remaining areas of Scope and activity are end-of-life preparations, responding to illness and communicating. Firstly, the area of end-of-life preparations is also connected with prioritising and achieving. In this type of Scope examples include 'getting your affairs in order sooner rather than later', 'putting your house in order' and 'to prepare for death'. Equally frequently, Patient's activity is related to responding to their illness, as in 'developing cancer' and 'you recover'. These differ from material processes of 'coping' mentioned earlier in that they involve a physical response such as 'bearing pain' rather than one of generally 'coping'. The final subgroup relates to communication, as 'you may want to practise what you will say'. Although related to verbal processes, this group involves more deliberate focus upon communication skills and practising verbal processes in order to be able to talk to children more effectively. It could be argued that this hints at another area in which Patient engages in the appropriate training, as advised by the writers, in order to be able to carry out certain activities more effectively.

To summarise Patient as Actor –Goal/+Scope, the key points which have emerged are a focus upon living, coping and dying. Clearly there are overlaps with other

process types in that several of these groups have emerged in other sections such as mental processes when thinking about daily activities or choosing new activities or mental and verbal processes regarding end-of-life choices. In relation to processes of coping, a pattern has started to emerge in the advice data in which very general processes of coping are applied to quite specific problems. For example, the Patient is represented as coping with a range of specific situations such as illness, treatment, side effects, relationships, living with cancer and coping alone. However, beyond the general process of 'coping', there is very little information given about the specific coping strategies applied to each of these situations.

Other minor areas in this group such as communication, researching and responding to illness have been found within other process types such as other material, mental and verbal processes. Similarly to mental processes, there appears to be a lower proportion of treatment related processes than anticipated for Patient.

A final consideration is how this set of material processes relate to Patient's other material processes. As shown in the table below, this can be divided between the three main types of material activity depending upon whether Patient acts upon a Goal and if so, what type of Goal.

Table 18: Patient as Actor

Patient as Actor	No	% age
Actor - goal / + scope	275	62
Actor + inanimate goal	150	34
Actor + animate goal	17	4
Total	**442**	**100**

The decision has been taken to treat each type of Actor separately rather than as one whole category in order to avoid an overly general or misleading impression of

Patient's participation as Actor. By separating out each type of Actor, the analysis can provide more insight into the data and Patient's participation. For example, when taken overall, Patient takes the participant role of Actor in almost 32% of their overall activity in the advice data and this would form by far the largest group. However, in most cases where Patient is Actor, they are not acting upon anyone or anything. The following table gives an overview of the key areas in which Patient acts, as well as the Goals they act upon and Scopes or areas they act in relation to. At a glance, it is clear that there is a significant amount of variation across process types in terms of what or who is affected by Patient's acts of doing. The most frequent animate Goal emerges as children and the most common inanimate Goal is information and texts. Of all three process types, the third column (-Goal/+Scope) is the largest and shows that the greatest area of activity for Patient as Actor in the advice data relates to daily activities and life. This represents the Patient in this data as living with dying, with the emphasis firmly upon living.

Table 19: A Comparison of Patient as Actor in Material Processes

Process / Type / Goal/Scope	Actor + animate Goal	Actor + inanimate Goal	Actor – Goal/+ Scope
Other – Children	35%		
Other – Friends and Family	23%		
Patient	23%		
Pets	6%		
Information/texts		18%	
Time		11%	
Feelings		11%	
Help and Support		6%	
Schedule/rota/plans		6%	
Words/conversation		5%	
Decisions/choices		5%	
Food		5%	
Power of Attorney/ a Will		3%	
Experience		3%	
State Departments		2%	
Walking aids		2%	
Symptoms/side effects		2%	
Advice		2%	
Questions		2%	
The link/button		2%	
Interest		2%	
Humour		1%	
Countries		1%	
My house		1%	
A camera		1%	
Daily activities/Life		1%	42%
Lips/mouth		1%	
Energy		1%	
Weight		1%	
Fluid		1%	
Noise		1%	
Genes		1%	
Independence		1%	
Dignity		1%	
Death/End-of-life			22%
Illness			10%
Treatment			9%
Research			6%
Emotions			4%
Steps/precautions			3%
Aims/priorities			1%
Communication about illness			1%
Total	**100%**	**100%**	**100%**

Table 9: Positive and Negative Emotion in States and Processes

	States with mental overtones of emotion Patient as Carrier	Mental processes of emotion Patient as Senser
Positive	10.5%	66%
Negative	89.5%	34%

There is a further frequency reversal regarding cognitive states and processes, with cognition being less likely within relational attributive states than mental processes. In the advice data this indicates that, for example, Patient is less likely to 'be confused' than 'to understand'.

There is further divergence with respect to states with overtones of desideration and perception in that there are no examples of either in relational processes, in contrast to a clear focus within the data amongst mental processes. This may be partly due to the fact that fewer options exist in the language by which to express desideration and perception via relational attributes. What can be seen from the advice data is that Patient is more likely to express their preferences in mental processes than as emotional attributes and that patients' increased role within decision-making as indicated in the literature (Townshend, 1990; Roberts, 1999; Wilkinson et al., 1999; Jansen et al., 2001; Department of Health, 2003; Tong et al., 2003; Ache and Wallace, 2009; Grande and Ewing, 2009; Daveson et al., 2011), is not evident within this group of relational processes.

A number of further final observations can be summarised on states with mental overtones. Most examples are emotion based, demonstrating 'an alternative construal of emotion' (Halliday and Matthiessen, 1999, p143), with some cognition, and no perception or desideration based states. Regarding emotion based states, the majority of states are negative, triggered by illness. In addition, the more frequent states for Patient of 'anger' and 'depression' coincide with two key stages of grief as outlined by Kübler-Ross in her work on death and dying (1973) but do not include other stages such as 'bargaining' and 'acceptance'.

Finally, the choice of the writers to encode mental responses as relational attributive processes rather than mental processes presents Patient in the less dynamic role of Carrier of mental states rather than the more dynamic role of Senser in a mental process. To some extent, the use of relational processes to encode mental attributes emerges as a common feature of the advice data which appears to sidestep mental processes, particularly processes of emotion. This may be an unmarked choice or simply a more conventional way of encoding emotions which represents Patient as a less explicitly 'emotional' entity. On the other hand, it be suggested to have almost the reverse effect and that by blurring mental activity with another process type and the domain of attribution, this can represent Patient 'emotionally' in more than one process type and lead to an increase in Patient's participation in an emotional capacity.

General States

In addition to states with mental overtones, a number of other attributes are ascribed to Patient in the advice data. The following set relates to states which can be defined as general, rather than with mental overtones or specific health states, and account for 30% of Patient's intensive attributes. These attributes can be categorised in broad terms of positive, negative or neutral, although this in itself is not necessarily straightforward. For example, to 'have choices' might ordinarily be analysed as a positive attribute. However, in the context of the current data 'People with cancer face a lot of choices about the future' refers to treatment and end-of-life choices and the necessity to make those choices. This places a less than positive interpretation upon the choices and the process of facing them and in this context, the nature of the choices may present the opposite polarity as these choices include whether to try further treatment, where to die or whether to be buried or cremated. With close consideration to context, the positive, negative or neutral nature of these states can be summarised as follows:

Table 10: Positive and Negative States in Intensive Relational Processes

Type of State	Example	No	%
Positive	you can still be **independent** in other ways	24	37
Neutral	it may be helpful for you to be **present** when they are told	22	33
Negative	they may become **a burden**	20	30
Total		**66**	**100**

The group which can be categorised as positive cover a wide range of attributes which relate to being peaceful, adaptable, independent, communicative, close, good, keen, in control and involved. Examples include, 'you feel more able to talk to your children', 'you can still be independent in other ways' and 'you to feel more in control of your situation'. Furthermore, a range of contexts can be identified such as personal relationships, communication, difficult times, counselling, everyday life and end-of-life. No particular pattern emerges except that positive states are associated with a range of health-related contexts from Patient disclosing their diagnosis to their children to end-of-life stages. Beyond health-related contexts, positive states also appear in contexts such as everyday life and personal relationships, indicating that positive states are not only present in health-related contexts, but are also generated by and experienced in contexts other than those of health and illness. Where given, Attributors for such positive states are personal openness and physical activity.

Regarding neutral states, these relate to being alone, careful, present and accustomed to feelings. Examples include, 'it may be helpful for you to be present when they are told' and 'you want to be left alone'. Half of the examples in this set also relate to how Patient feels but appear as 'how you feel', 'what you feel' or 'the way you feel' and so without a specified adjective it is not possible to assign them to either positive or negative states. In this respect, it could be argued that the total number of neutral states has therefore been inflated. However, the fact remains that by not attaching specifically positive or negative attributes to Patient's states in these examples, the writers have chosen to represent these attributes as neutral.

This suggests a reluctance at times on the part of the writers to be overly prescriptive in relation to all states, although a clearer indication of how Patient feels emerges from states with mental overtones. The typical contexts for these general states are communication, everyday activity and being in company or alone.

The final set of general states relates to those which can be regarded as more negative. These include examples such as 'they may become a burden', 'people with cancer are poor insurance risks' and 'Some people are more prone to developing a cancer'. Similarly to positive states, a range of contexts can be identified such as before and after diagnosis, communication, the illness, living with cancer, work and end-of-life. A further feature of this set is that it contains states which might not be considered negative in another context, such as to 'face a lot of choices'.

When comparing positive and negative states, it is possible to see which contexts these occur within and where there is a degree of overlap or divergence, as shown below.

Positive	**Both**	**Negative**
personal relationships		before diagnosis
difficult times	communication	illness
counselling	end-of-life	living with cancer
everyday life		work

Fig. 17 Contexts of Positive and Negative States

Health states

Patient attributes which can be categorised as health states account for only slightly less than the previous category of general states, comprising 29% of intensive attributes. Within this category, health states are taken to refer to physical states. Although it is acknowledged that 'health' includes mental as well as physical health, examples of states related to mental health have been analysed within states with mental overtones. Typical examples of health states include, 'someone who is ill', 'Will I be in pain?' and 'If you feel well enough' and cover a range of states from gaining strength and physical improvement to terminal illness and physical deterioration. This set can be divided generally between positive and negative health states, accounting for 24% and 76% respectively.

Perhaps not surprisingly, health states are considerably more likely to be negative than positive for Patient. The most common negative health state relates to physical dependence or inability, as in 'being physically dependent on others' and 'they get less able to do things'. This is followed by Patient being 'ill' or 'terminally ill', as in 'Sometimes I will feel ill' and 'a close friend or relative who is terminally ill with cancer', representing Patient as being defined by their illness. Equally as common as illness is the state of 'weakness', found in 'people feel very weak' and 'they get weaker'. The next most common negative health state is that of being 'tired' or 'exhausted', which connects with the previous category of 'weakness'. A further type of health state is that of being 'in pain', followed by other isolated but not unrelated states of being or feeling 'sensitive' 'cold', 'old', 'slow', 'unconscious' and 'dead'. The overall combination of these attributes represents Patient in ill health and in a process of physical deterioration; or 'reduced role function' (Johnsen, et al., 2009, p496) ranging from losing ability and mobility to death, as shown below.

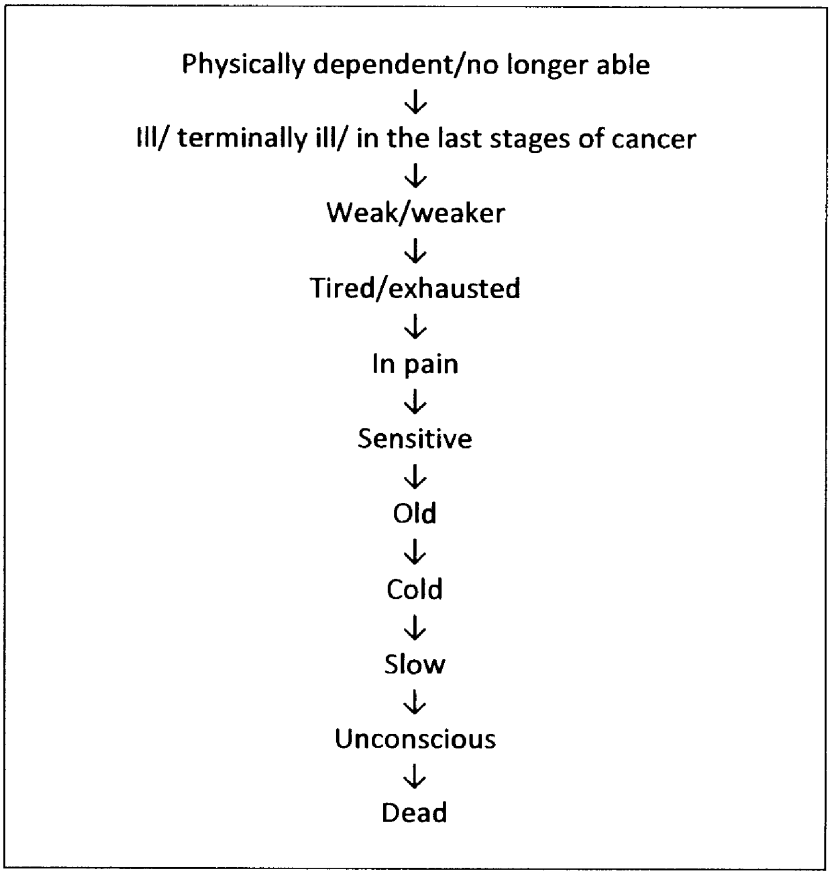


Fig. 18 The Path of Negative Health States

In contrast, more positive health states can be found in examples such as 'you feel well again' and 'you feel strong enough'. This set follows the opposite path of the negative health states, ranging from 'well' to 'cured', with Attributors being 'medicine', 'activity', and 'physical exercise'.

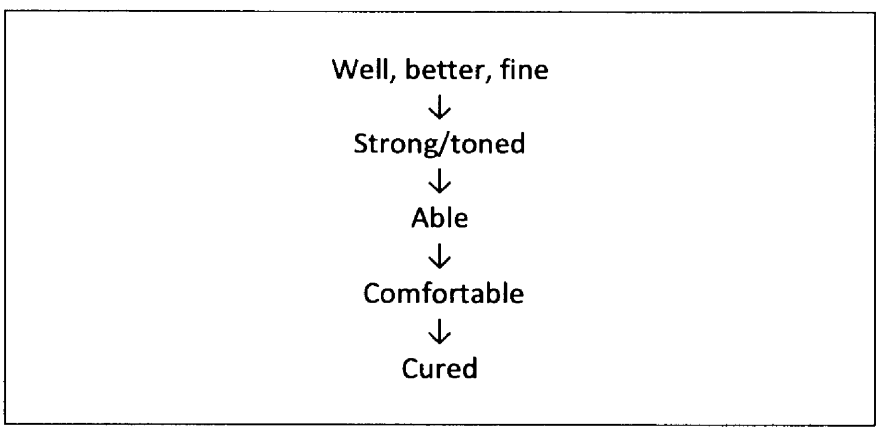


Fig. 19 The Path of Positive Health States

It is also of interest that these positive health states can be coupled with certain negative health states mentioned previously to form almost antonymous pairs, as indicated below.

Well, better, fine	Ill
↓	↓
Strong/toned	Weak
↓	↓
Able	No longer able
↓	↓
Comfortable	In pain
↓	↓
Cured	Dead

Fig. 20 Positive and Negative Health State Pairings

Personal Qualities

The next and final group of intensive attributes relates to personal qualities. Although this accounts for only 5% of intensive attributes, it offers some insight into the personal qualities of Patient, as ascribed by the writers of the advice texts. In terms of polarity, these qualities are overwhelmingly positive with Patient being described as 'positive' in over 40% of instances. Most of the remaining personal qualities are correspondingly positive, as in 'honest', 'cheerful' and 'optimistic'. Only one quality might be regarded as neutral, that being 'religious'. Finally, there is one example of a negative quality to be found in 'not cheerful'. However, the overall representation of Patient's personal qualities is one in which Patient appears as mostly positive in outlook, attitude and behaviour, with a glimpse of that positivity slipping only very rarely.

4.2.2 Possessive Attributes

Having considered intensive attributes for Patient which account for over 70% of overall attributes, the next key type of attribute to be considered is that of

possessive attributes. These are concerned with ownership and belonging, what Patient 'has' rather than what he/she 'is' or 'feels', and form 26% of Patient's relational attributive processes. The most evident type of attribute is 'cancer' or 'illness', which comprises one third of all of Patient's possessive attributes. The table below lists all attribute types in order of frequency, arranged according to groups of related attributes such as 'cancer' and 'symptoms' together to align associated attributes more closely.

Table 11: Associated Attributes in Possessive Relational Processes

Possessive Attributes	No	%	%
Cancer/illness	27	33	
Symptoms/side effects	6	7	40
Treatment	4	5	
Care/help/support	11	14	26
Advice/information	6	7	
Feelings	8	10	
Thoughts	2	3	16
Faith	2	3	
Money/things	5	6	
Time	4	5	
People	3	4	
Control	1	1	
Skills	1	1	
Energy	1	1	
	81	**100**	

As mentioned previously, the most common attribute which Patient possesses is their 'cancer', 'illness' or 'a serious illness', with the more specific illness-related attributes of side effects and symptoms such as 'you have no strength' and 'you have pain', accounting for 40% of this group. The frequency of such possessive attributes indicates that the advice data defines Patient primarily in terms of their

illness and symptoms. In view of these predominant attributes, Patient meets what can be described as certain 'role expectations' (Williams, 2004) by virtue of having an illness and symptoms. However, owing to the nature of their illness, Patient is unable to meet the second key part of that role expectation because as a terminal cancer patient, they are unable to get better. So whilst these attributes represent Patient within 'the sick role' (Armstrong, 1994), despite fulfilling the obligation of wanting to get better, Patient in this context of health may be unable to achieve that particular goal. The inability of Patient to bridge this gap is one of central importance to this study as is how the 'role expectations' placed upon them may vary from those placed upon Patients in other contexts of health, such as where recovery is a possibility.

Following on from this, over a quarter of Patient's possessive attributes relate to 'care, advice and treatment' which have been grouped together as attributes which are designed to be helpful and supportive for Patient. Examples include 'People may need quite a lot of physical help', 'as much help and advice as you need' and 'I need a different type of treatment'. Care related attributes are the largest component of this set, accounting for 14% of possessive attributes, with advice and information comprising 7%. In keeping with material processes, treatment is relatively infrequent and accounts for only 5% of this group. A particular feature of this group is that 64% of these possessive attributes appear in terms of what Patient 'needs' rather than what Patient 'has' and so in this respect can be regarded the writers' compilation of Patient's needs or as 'expected' rather than necessarily 'actual' attributes.

The next set includes attributes of 'feelings, thoughts and faith' and are related to Patient's internal attributes of feelings, thought and beliefs, such as 'some of the emotions that you have' and 'you may have thoughts which are like dreams'. These make up 16% of the total possessive attributes and there is a degree of overlap with mental processes and states with mental attributes in that these exist in the mind of the Patient, rather than the external world. In comparison with intensive states with mental overtones, these attributes are usually referred to generically as

'feelings' or 'emotions' rather than as a specific feeling such as 'love'. Although this is a feature of some states with mental overtones, the extent to which feelings have been generalised is far greater in this set. Examples of feelings which Patient has which are specified are positive or presented positively, such as 'they have a better appreciation of the ordinary things of life' and 'you have a faith'.

The remaining possessive attributes for Patient are less frequent and do not combine to form any obvious groups. The first relates to possessions such as money and belongings, as in 'your money and things you own'. Patient's possession of 'time' also appears, as in 'you have some time to yourself', 'you haven't had time to think' and 'you need time', which presents time as an attribute which Patient has, does not have and also needs. A further possessive attribute relates to 'people', such as 'Who would you like to have around you?' and 'you have children'. The final attributes appear once only and relate to 'control', 'skills' and 'energy'. The first attribute appears as something which Patient does not have, as in 'hardly something you have any control over'. This represents Patient as having an 'external locus of control' whereby 'they do not feel in control of events' (Banyard, 1996, p174); a representation which does not take into account findings which suggest the contrary in relation to illness, treatment and end-of-life choices (Lewis, 1989; Henselmans, 2010; Beaver and Booth, 2007). 'Skills' appear in terms of what Patient needs rather than possesses, whilst 'energy' appears as an attribute which Patient has as increase of under certain conditions, as in 'they have more energy when they take part in physical activities'. This contrasts with earlier examples of symptoms and negative health states involving fatigue and it should be emphasised that Patient only has increased energy after physical activities and this may not always be possible for Patients with advanced cancer.

A final approach to categorising these possessive attributes is according to whether they appear to be positive, negative or neutral attributes. These have been categorised as such where it was felt that the polarity was clear, such as 'cancer' and 'close friend or relative', with more ambiguous examples being allocated to the neutral group. The overall distribution of possessive attributes according to polarity

represents Patient with 43% positive attributes, 40% negative attributes and 17% neutral. Positive examples include 'help', 'support' 'time' and 'energy', whilst negative attributes include 'illness', 'pain', 'symptoms' and 'trouble' and it is of some interest that attributes of both types are almost equal in frequency with a slight incline towards more positive attributes. This represents Patient as achieving a relative balance between attributes of both types despite the fact that 65% of all the attributes in this group are directly or indirectly illness related.

4.2.3 Circumstantial Attributes

The final group of attributes pertain to those labelled circumstantial, related to location, time, quantity and matter. Examples from the advice data include 'I had been under the hospital for 18 months', 'you have never been in hospital', 'some people stay in their own homes' and 'you have to stay in bed'. In total these account for only 3% of all patient attributes and describe locations such as hospital, home or being in bed. In some cases other people share the same location and they are a key part of the circumstantial attribute, as in 'you are with the doctor'. Overall, a link can be made between the circumstantial location and context of health, particularly in relation to where Patient receives treatment or care.

In conclusion regarding relational processes, certain attributes may be predictable and the initial hypothesis was that the predominant attributes of Patient would be their illness and resultant symptoms. The extent to which these have emerged is that 31% of Patient attributes are directly related to illness and symptoms, as indicated below. Perhaps given that medical advice websites are primarily concerned with giving advice on medical matters such as symptoms, it is not surprising that this constitutes the leading type of attribute.

Table 12: Overview of Illness Related Patient Attributes

Type	No	% of Patient Attributes
Intensive - Health states	62	31
Possessive – cancer/ illness	27	
Symptoms/side effects	6	
Total	95	

In addition to the extent to which these predictable attributes appear, what is also of interest is which other types of attributes emerge. The two emerging attributes are states with mental overtones and general states. Within the former, the dominant mental overtones relate to emotions and these attributes tend towards negative emotions far more than positive. In total, states with mental overtones account for over 25% of Patient's total attributes. The cumulative effect of these relational processes with mental overtones in addition to mental processes is that there is greater focus upon Patient's feelings. In fact, if mental processes and relational processes with mental overtones are combined, this would form the second largest group within Patient's overall activity in the advice data. It accounts for 21% of Patient's total participation here and is greater in number than Patient as Senser in all types of mental processes. To be more specific regarding mental processes of emotion and attributes of an emotional nature, these account for 7% of Patient's total participation, significantly increasing Patient's participation in an emotional capacity. For this to be a chosen focal point within medical advice texts may not necessarily have been predicted and suggests a change in the scope of advice texts such as these which now aim to advise Patient beyond the purely medical facts, thereby widening the remit of advice to include emotional as well as medical matters.

General states account for 21% of Patient's total attributes and can be divided broadly equally between positive, negative and neutral states, with a slight incline towards positive. Although it was possible that other non-medical attributes might emerge such as children, other family members or hobbies, these have not appeared in significant numbers in the advice data.

Furthermore, there is evidence of relational processes being used in a way which is complementary to other process types within the data. For example, relational processes of attribution for Patient have revealed aspects of Patient experience such as pain, fatigue or depression which may have been anticipated within other process types such as mental or material. These aspects are certainly evident in the advice data but not necessarily within the process type which they may initially have been expected. Whilst they have not been overlooked, when they do appear, Patient is in the less dynamic role of Carrier as opposed to Senser or Actor.

Moreover, in representing Patient in transitivity slots of reduced dynamism, these examples indicate some compliance with more traditional representations of patients within medical texts whereby Patient is typically acted upon, spoken to and possesses an illness with symptoms. Evidently, this representation is not entirely absent from the current advice data but it is not the predominant representation of Patient which emerges. The overall representation of Patient in relational processes which unfolds in the advice data is more complex than the mere carrying of health states. Although the overview of possessive attributes in the advice data defines Patient primarily in terms of their illness and symptoms, a range of other types of relational processes broaden the representation of Patient beyond the traditional parameters of the biomedical model and the medical gaze, to include states with mental overtones, more general states and personal qualities. These serve to represent Patient in a way which has broken with the tradition of medical texts of the past, and represents Patient as a person beyond the illness.

A further key finding is that whilst Patient possesses the prerequisite qualities of the 'sick role' (Parsons, 1951; Armstrong, 1994), they are not in a position to fully

realise that role in terms of illness recovery and it may be this shortfall and the writers' recognition of it, which perhaps leads the increasing emphasis upon Patient's mental activity in the advice data. The possibility of a causal relation between the context of health of terminal illness and the accompanying representation of Patient's mental activity, particularly of an emotional nature, should not be discounted. In contrast to Patients in a non-terminal context of health, the 'role expectations' of recovery are not applicable to the Patient in the current data. However, it could be argued that the representations of mental activity places a unique set of emotion-related 'role expectations' upon the Patient with terminal illness.

Finally, the analysis of relational attributive processes suggests that these processes are not as straightforward as first imagined. They reveal Patient and their attributes to be of greater significance than the process of 'being' or 'having'. Moreover, the analytical outcome is not simply related to what Patient 'is' or 'has' but the overtones of and connections to other process types such as material or mental. They demonstrate the function of relational processes in bridging material and mental processes and experience; the convergence of Patient's 'outer experience' of the external world and 'inner experience' of the internal world of their own mind. They often reveal this overlap and how 'outer experience and this inner experience may be construed by 'relational' clauses; but they model this experience as 'being' rather than 'doing' or 'sensing' (Halliday and Matthiessen, 2004, p211).

4.3 Patient as Actor – Goal/+Scope

The second most frequent role for Patient is as Actor without a Goal or with Scope. This group accounts for almost 20% of Patient's overall participation within the advice data and there are certain subgroups within this larger group which have been categorised according to the nature of the activity engaged in. An overview of these can be found below. In terms of whether these processes are intentional or involuntary, the former category accounts for 80% of this group. In cases where processes are involuntary, in the vast majority these are processes connected with dying.

Table 13: Patient as Actor – Goal/+ Scope

Process Group	No	%
Living/Daily activities	60	21
Coping with	36	13
Adjusting	35	13
Living/New activities	33	12
Dying related	34	12
Dying	21	8
Having treatment	20	7
Researching	14	5
Prioritising/Achieving	11	4
End-of-life preparing	5	2
Reacting to illness	5	2
Communicating	3	1
Living/Surviving	2	1
Total	**279**	**100**

These are the key groups of processes in order of frequency. However, a clearer overview can be gained by combining certain groups which incline towards each other semantically. This is shown in the table below and provides a more cohesive overview of Patient as Actor, showing the three key areas of activity in this group in bold, related to living, coping and dying, with living and coping both being more prevalent than dying.

Table 14: Patient as Actor – Goal/+ Scope Resorted

Process Group	No	No	%	%
Living/Daily activities	60	**95**	21	**33**
Living/New activities	33		11	
Living/surviving	2		1	
Coping	36	**71**	13	**26**
Adjusting	35		13	
Dying	21	**55**	8	**20**
Dying related	34		12	
Having treatment	20	20	7	7
Researching	14	14	5	5
Prioritising/Achieving	11	11	4	4
End-of-life preparing	5	5	2	2
Reacting to illness	5	5	2	2
Communicating	3	3	1	1
Total	**279**	**279**	**100**	**100**

As the table shows, areas can be grouped together in general terms such as 'living' comprised of both 'everyday living and routine activities' and 'living life to the full and new activities'. Examples of the former include 'just trying to carry out ordinary daily activities' and to 'keep up with your daily routine' and simple everyday tasks such as 'getting up', 'washing' and 'dressing'. This group also includes actions which take place outside of the home such as 'returning to work' and 'going to work'. Together they conform to the pattern established in other material and mental processes and previous research in which the maintenance of daily routine provides a sense of control for Patient and helps them to create meaning via day-to-day activities (Armstrong-Coster, 2004; Kennedy and Lloyd-Williams, 2009b), which La Cour et al. refer to as 'routines and continuity as a platform for agency' (2009, p474). In turn, this sense of control may influence Patient's ability to cope with

their illness (Forshaw, 2002) because 'patients who can find a sense of meaning ... adjust well to their cancer' (WHO, 2002, p21).

However, it is also possible to divide these processes into actions which Patient can carry out with ease and those which they struggle with or are unable to carry out. Examples of this are 'I've always done the cooking', 'being helped to go to the toilet' and 'some people can't return to their jobs because of their cancer'. A breakdown of these processes viewed in this way is shown in table 15.

Table 15: Patient as Actor – Goal/+ Scope: Can Do → Cannot Do Overview

Nature of Activity	No	%
Can do	42	70
Struggles to do	11	18
Cannot do	7	12
Total	**60**	**100**

Overall this shows that Patient can do more of the activities than they struggle with or cannot do. Nevertheless, this also represents a sequence of events characterised by deterioration of Patient's active participation in certain everyday activities (Taylor and Currow, 2003). For instance, simple everyday activities such as 'getting up', 'washing' or 'getting dressed' are examples of actions which usually go unmentioned and yet are specifically highlighted in this section. This may possibly be because these actions now present more of a challenge than usual and have become part of 'living with cancer' where maintaining routine is important and Patient is advised 'to continue my normal activities' as far as possible. How far this can be reasonably expected can be summed up by the example from the data 'some people do manage to lead an almost normal life during their treatment'. Furthermore adjusting to day-to-day life, particularly after treatment, is an area in which patients have recommended greater support and more specific advice (National Cancer Alliance, 2001; 2002).

This suggests a general focus upon living as a key area of activity for Patient but with a division between life before; as usual and life now; with revisions. It could therefore be argued that daily activities form part of a crucial link between the two time frames and are instrumental in navigating the transition from life before and after the cancer diagnosis so that Patient can adapt to changes in their life now that they are living with cancer. To be more specific, studies have shown that 'by emphasizing routines the person with advanced cancer may experience a sense of hope, embedded in moments of activity repeatedly returning in daily life ... that through familiar activity such as cooking, the participants found ways to construct and embed new meanings in an activity they had pursued before their illness' (La Cour et al., 2009, p 477).

The other 'living' group, comprising 11% overall, relates to living life to the full and activities which may be entirely new to Patient or something which they have always wanted to do. Examples of this are 'people with cancer can live each day to the fullest' and 'new, fun things that they have never done before'. This group can be further divided between living life to the full in general or specific actions such as taking up hobbies, doing sport and travelling. The general subgroup accounts for 18% of this set whilst the greatest emphasis is upon the latter, more specific type of activity accounting for 82%. This suggests that there is a degree of emphasis in the data upon positive activity, designed to help Patient enjoy life and experience fun and engage in new activities, as well as reassurance from familiar activities.

One final set of 'living' related processes appears and refers to living in terms of survival, as in 'What percentage of patients with my type of tumor live five years or more?' In total these account for only 1% of Patient's activity related to 'living' and this indicates that there is far greater emphasis on living with cancer or living life to the full despite cancer than upon surviving cancer. The advice data therefore represents Patient as more likely to do something they have always wanted to do such as 'ride in a hot air balloon' than they might be to 'live five years or more'.

The second largest group of Patient's activity as Actor –Goal/+Scope refers to processes of coping and adjustment. This emerges as a significant area of material activity and forms 26% of this group. They can be equally divided between coping and adjusting with examples of each being 'me and my family deal with the disease' and 'adjusting to life after cancer treatment'. The first subgroup offers advice on coping in the general sense rather than any specific coping strategies and this is reflected in the nature of the processes, shown below. In the majority of examples, there is a uniformity of process in that 'cope with' or 'deal with' make up almost 80% of the examples in this subgroup.

Table 16a: Patient as Actor – Goal/+ Scope in 'Coping' Processes

Material Process	**No**	**%**
Cope with	20	56
Deal with	8	22
Manage etc	8	22
Total	**36**	**100**

Table 16b: Patient as Actor – Goal/+ Scope in 'Coping' Processes

Scope	**No**	**%**
Illness	20	56
Life/experience etc	7	19
Emotions	6	17
Treatment	3	8
Total	**36**	**100**

Where Scope appears in these processes, there are four key contexts for Patient 'coping', as shown in the table above. Perhaps unsurprisingly, the most significant area of coping, accounting for over 50%, relates to 'illness', as in 'you cope better with the illness'. Here, 'illness' is being treated as Scope rather than circumstance because 'deal with' or 'cope with' have been analysed as prepositional phrasal verbs, not be used without 'with' and followed by 'something' which is being 'coped

with'. In terms of coping with illness, there is believed to be a correlation between the employment of coping strategies and the level of threat presented by the illness (Kelly, 2004) and given that terminal illness presents a significantly high level of threat, it might be expected that Patient will employ various coping strategies and that these processes would be evident in the data. It has also been argued that illness presents a particular and fundamental challenge for the patient whereby diagnosing an illness creates a 'new 'master' identity for the patient' to cope with and adapt to (Armstrong, 1994, p69). As Killeen claims in her reflections on cancer and personhood, 'just as good health means everything to a person, illness alters the life of the entire individual' (2004, p203). This will be explored further when considering relational processes and Patient self-definition.

Illness as Scope is followed by the more general group of 'life, experience and your situation' and conforms to the rather generalised nature of the advice being given. Examples of this are 'you can begin to cope with life again' and 'someone who has been through the same experience'. Compared to 'illness' as Scope, this group is characterised by the more general nature of the Scope involved and although there is some variation within the group, it can be argued that they are all influenced by and connected to 'illness'. Patient's life is now one in which 'living with terminal illness' is an essential feature and their experience and situation both refer to 'living with terminal illness'. In this respect, it can be claimed that illness forms a common thread running through the problems which Patient has to cope with (Armstrong-Coster, 2004), as shown by the type of Scope involved in material processes of coping.

Emotions and feelings form the third Scope group and although there may be an overlap with mental processes of emotion, in the case of the process 'to cope' in this group, it is unclear as to whether this involves purely mental activity or mental and material activity. For example, 'to accept your situation' can be categorised as a mental process of emotion, whereas 'to cope with your emotions' may require practical material activity in addition to mental activity. In addition, 'coping' has been defined as 'cognitive and behavioural efforts to manage demands that are

appraised as taxing an individual's resources' (deFaye et al., 2006, p240). Owing to this overlap, processes of coping and managing have been ascribed to the material category unless clearly indicated as purely mental activity.

These processes also include examples which indicate difficulty in coping such as 'the emotions and feelings do not get easier to deal with' and 'these emotions can be frightening and difficult to deal with' and introduce an element of Patient coping, but not with ease. Whilst these examples suggest that Patient is being represented as not necessarily coping comfortably, there are no examples in which Patient fails to cope with their emotions as found in medical and psychiatric studies (Chochinov et al., 1998; Weisman and Worden, 1986).

Finally, in 8% of this subgroup Patient is involved in coping with 'treatment', as in 'you are also coping with the treatment'. There are fewer examples of treatment in Patient's processes of coping, suggesting an assumption that treatment may be an area in which Patient is not necessarily expected to always cope. Alternatively, processes of coping may not be emphasised because Patient is expected to cope with treatment because, despite its side effects, it is for Patient's benefit. In fact, Patient is six times more likely to engage in more general material processes such as 'having treatment' than they are to 'cope with treatment'.

Similarly to processes of 'coping', those of 'adjusting' tend to be of a general nature, as in 'you can adjust to your situation' and 'you adjust to life after treatment'. They can be characterised as processes in which Patient adapts to living with cancer. However, there are also examples of more specific activities such as 'to set small achievable goals' and 'Do I need to take any special precautions at home?' in which Patient makes the necessary alterations to their home, lifestyle and approach to life in order to ensure greater quality of life. Such examples appear to recognise the relationship between 'patients' coping resources and quality of life' (Mårtensson et al., 2008, p350). They can also be seen as examples of adaptation and adjustment which Patient engages in and are regarded as 'processes of

adjusting to demands of living' and attempts to 'achieve the outcomes of coping efforts' (Somerfield et al., 1999, p 334).

The literature highlights several approaches to coping with and adapting to illness such as denial, avoidance and resignation (Kelly, 2004) and it is not necessarily coincidental that these can be seen to overlap with the first and last of five key stages in reacting to terminal illness; namely, denial, anger, bargaining, depression and acceptance (Kübler-Ross, 1973). Similarly, de Faye et al. (2006) identified categories of 'problem-focused' and 'emotion-focused' strategies to coping with advanced cancer. According to Bradley et al., coping 'has two major functions: dealing with the problem that is causing distress (problem-focused coping) and regulating emotion (emotion-focused coping)' (2010, p1211). Furthermore, the two approaches to coping have different aims or 'different targets of action. One is the offending situation; the other is our emotional state' (Lazarus and Lazarus, 2006, p58).

Whilst more recent literature suggests the need for a range of coping devices, this range is not apparent in the data owing to the very general nature of the advice on coping. De Faye et al (2006) highlight this as a weakness within psycho-oncology, suggesting that in some research into patient coping strategies, there has been a tendency towards an 'overly broad' approach (p236). This concurs with the findings in the advice data in that Patients are represented as coping with a number of things but not given advice on specific coping strategies. Therefore, it could be claimed that the advice does not take into account the breadth of specific strategies required to actually 'cope with' the illness and its associated challenges and so fails to adopt a sufficiently 'problem-specific' approach to coping with cancer (Somerfield et al, 1999). Nor does it fully take into consideration that a degree of flexibility is required regarding the application of coping strategies by different people to these challenges over a period of time (Brennan, 2001 and de Faye et al., 2006) and 'the fact that people with advanced cancer must cope concurrently with multiple problems across different dimensions of stress' (de Faye et al., 2006, p240).

De Faye et al. (2006) also divided the specific problems being coped with into physical, social and existential categories. Each of these is represented broadly within the advice data in terms of the type of Scope which Patient copes with, as shown in the examples below. The fact that all three types of problems can be found but the coping and adjustment processes remain rather general, would support the claim that despite the range of specific problems Patient has to cope with, there is a shortfall in specific and corresponding coping strategies (de Faye et al., 2006).

Type of Problem being coped with	Example of Equivalent in Scope
Physical	- coping with your illness - you are also coping with the side effects
Social	- treatment may affect how you relate to them
Existential	- you adjust to living with your diagnosis - you haven't been able to manage on your own

Fig. 21 Patient as Actor –Goal/+Scope: 'dimensions of stress' (adapted from de Faye et al., 2006)

After living and coping, the third group of material activity for Patient involves dying and this accounts for 20% of Patient's overall activity in material processes without Goal. The two main categories within this group relate to processes in which 'dying' is explicitly mentioned and secondly, those which can be regarded as 'dying related' activity. For example, 'you may die suddenly' differs from 'the person's body will relax completely' in that the former describes the process of dying, whereas the latter describes a process which appears as a possible part of the process of dying. The former 'dying' group is relatively easy to identify as it usually involves the verb 'to die'. Interestingly, the lexical choice of 'die' in this group also complies with advice given regarding verbal processes on the use of the word 'death' rather than euphemisms. This demonstrates that the writers are employing a similarly unambiguous and direct choice when advising Patient on this material process as they have advised Patient to employ when explaining the situation to other people. Examples include, 'you may die within the next few months' and 'how and where

you would like to die'. These also represent Patient in processes of dying characterised by 'resignation' (Kelly, 2004) and 'acceptance' (Kübler-Ross, 1973), which are thought to appear within the final stages of coping and adapting to terminal illness.

The second group includes a wider range of processes with the common theme of being related to death. When considered out of context, these processes may not immediately seem connected to dying but can be grouped together within this context because they describe actions which take place as part of the dying process. Further examples include, 'people move into a phase where their sleep becomes deeper', 'your muscles may waste away' and 'a person stops drinking'. These processes offer a more detailed description of the mechanics of dying and what Patient can expect to happen.

The table below shows that 'dying related' processes are more frequent than 'dying' itself. On first impressions, this might have been anticipated on the grounds of death being an uncomfortable topic and one which is more likely to be addressed and referred to euphemistically than directly. However, this does not appear to be the case in the current data. On the contrary, the presence of more 'death related' processes such as 'a person stops eating' serve to describe in more explicit detail some of the physical processes which accompany dying. Therefore, it cannot be argued that by using words other than 'die' or referring to other processes, the issue of death is being avoided. A more accurate explanation is that Patient is being advised on and prepared for what will happen in the final stages of life through the explicit description of the processes involved in dying. Patient's knowledge and understanding of the dying process has been stipulated as one of the principles of a good death (Johnston, 2004a) and it can be argued that such knowledge and understanding are an essential component of Kübler-Ross' 'acceptance' stage (1973).

Table 17: Patient as Actor – Goal/+ Scope in 'Dying' Processes

Process	No	%
Dying	21	38
Dying related	34	62
Total	**55**	**100**

A further defining feature is the emphasis upon activities which Patient can no longer do or their body will stop doing. For example, 'people are not able to get out of bed at all', represents Patient as no longer able to do something they once could and this represents the situation differently from simply 'they lie still'. Within the group of 'dying related' processes over 40% are concerned with actions which Patient can no longer do or their body has simply stopped doing such as 'you no longer fight'. This gives significant coverage to the loss of physical function which is likely to occur prior to dying, referred to as the 'gradual deterioration in functional status' (2003, p31). When compared to the key indicators specified by Ellershaw and Ward (2003) in the diagnosis of dying, similarities can be found with examples in the advice data. This suggest that just as health professionals are being trained in the identification of these key indicators to enable accurate and prompt diagnosis of dying, patients are also being trained and prepared as their awareness of these indicators is being increased.

Clinical Indicator	Example from advice data
The patient becomes bedbound	People are not able to get out of bed at all
The patient is semicomatose	They drift in and out of consciousness
The patient is able to take only sips of fluid	Once a person stops drinking
The patient is no longer able to take oral drugs	Once a person stops eating

Fig. 22 Key Indicators of the Dying Phase (adapted from Ellershaw and Ward 2003)

The next group relates to 'treatment' and accounts for 7% of Patient's participation in these material processes. Examples include 'the operation I had' and 'me ... receiving a different type of treatment'. As with mental processes, the quantity seems lower than anticipated and suggests that although the focus upon treatment may be more frequent in some process types such as verbal, it does not necessarily apply equally to other process types such as mental and in this case, material. In general, the processes involved in this group are generalised rather than medicalised but overall can be seen as covering a range of actions which form a chain of events in the treatment trajectory, as illustrated below. However, one limitation of this overview as presented below is that it presents treatment as a linear process when in truth it may be less linear and more cyclical at times, depending on the patient's individual trajectory.

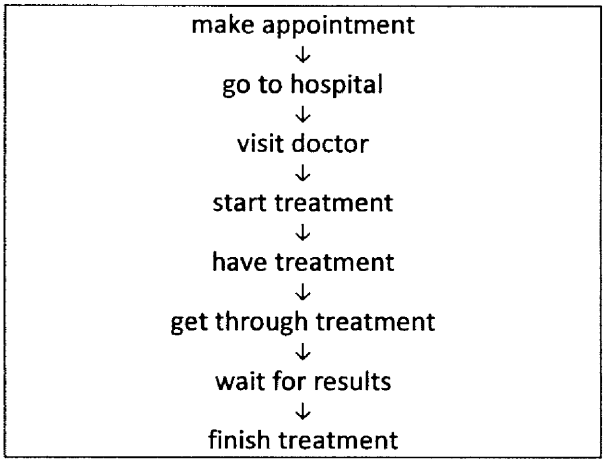


Fig. 23 Patient as Actor –Goal/+Scope: the treatment trajectory

The remaining groups fall below 5% or less of Patient's participation in material processes -Goal/+Scope and so will be dealt with briefly. The first of these relates to research activity in which Patient is engaged in activities such as accessing sources of help, visiting websites and reading. Examples include, 'read more' and 'a number of sources of help you can turn to for practical advice, medical information, emotional support or spiritual comfort'. This group has some connection with other material research processes in which Patient acts upon information based Goals and related mental processes in which Patient learns about or understands their illness and treatment. In this group, there is also a certain emphasis upon website

navigation processes in particular, as in 'looking on the Internet' and 'you can choose from the menu below'. In this respect, Patient is represented as actively engaged not only in research, but specifically online research and presents a patient profile in which internet use is assumed.

The next group relates to prioritising and achieving in which Patient is engaged in 'working towards something' and 'what they want to achieve'. These can be seen as related to other material processes such as 'setting goals' and 'setting your priorities' and mental processes in which Patient thinks about and makes choices according to their priorities. Combined, they carry a common thread of considering priorities, planning and then acting upon both in order for Patient to achieve what is important to them. This represents Patient as acting in view of their revised priorities and living life according to these priorities. There is also some coverage of Patient's limitations in this area in examples such as 'you cannot meet other aims'.

The three remaining areas of Scope and activity are end-of-life preparations, responding to illness and communicating. Firstly, the area of end-of-life preparations is also connected with prioritising and achieving. In this type of Scope examples include 'getting your affairs in order sooner rather than later', 'putting your house in order' and 'to prepare for death'. Equally frequently, Patient's activity is related to responding to their illness, as in 'developing cancer' and 'you recover'. These differ from material processes of 'coping' mentioned earlier in that they involve a physical response such as 'bearing pain' rather than one of generally 'coping'. The final subgroup relates to communication, as 'you may want to practise what you will say'. Although related to verbal processes, this group involves more deliberate focus upon communication skills and practising verbal processes in order to be able to talk to children more effectively. It could be argued that this hints at another area in which Patient engages in the appropriate training, as advised by the writers, in order to be able to carry out certain activities more effectively.

To summarise Patient as Actor –Goal/+Scope, the key points which have emerged are a focus upon living, coping and dying. Clearly there are overlaps with other

process types in that several of these groups have emerged in other sections such as mental processes when thinking about daily activities or choosing new activities or mental and verbal processes regarding end-of-life choices. In relation to processes of coping, a pattern has started to emerge in the advice data in which very general processes of coping are applied to quite specific problems. For example, the Patient is represented as coping with a range of specific situations such as illness, treatment, side effects, relationships, living with cancer and coping alone. However, beyond the general process of 'coping', there is very little information given about the specific coping strategies applied to each of these situations.

Other minor areas in this group such as communication, researching and responding to illness have been found within other process types such as other material, mental and verbal processes. Similarly to mental processes, there appears to be a lower proportion of treatment related processes than anticipated for Patient.

A final consideration is how this set of material processes relate to Patient's other material processes. As shown in the table below, this can be divided between the three main types of material activity depending upon whether Patient acts upon a Goal and if so, what type of Goal.

Table 18: Patient as Actor

Patient as Actor	No	% age
Actor - goal / + scope	275	62
Actor + inanimate goal	150	34
Actor + animate goal	17	4
Total	**442**	**100**

The decision has been taken to treat each type of Actor separately rather than as one whole category in order to avoid an overly general or misleading impression of

Patient's participation as Actor. By separating out each type of Actor, the analysis can provide more insight into the data and Patient's participation. For example, when taken overall, Patient takes the participant role of Actor in almost 32% of their overall activity in the advice data and this would form by far the largest group. However, in most cases where Patient is Actor, they are not acting upon anyone or anything. The following table gives an overview of the key areas in which Patient acts, as well as the Goals they act upon and Scopes or areas they act in relation to. At a glance, it is clear that there is a significant amount of variation across process types in terms of what or who is affected by Patient's acts of doing. The most frequent animate Goal emerges as children and the most common inanimate Goal is information and texts. Of all three process types, the third column (-Goal/+Scope) is the largest and shows that the greatest area of activity for Patient as Actor in the advice data relates to daily activities and life. This represents the Patient in this data as living with dying, with the emphasis firmly upon living.

Table 19: A Comparison of Patient as Actor in Material Processes

Process Type / Goal/Scope	Actor + animate Goal	Actor + inanimate Goal	Actor – Goal/+ Scope
Other – Children	35%		
Other – Friends and Family	23%		
Patient	23%		
Pets	6%		
Information/texts		18%	
Time		11%	
Feelings		11%	
Help and Support		6%	
Schedule/rota/plans		6%	
Words/conversation		5%	
Decisions/choices		5%	
Food		5%	
Power of Attorney/ a Will		3%	
Experience		3%	
State Departments		2%	
Walking aids		2%	
Symptoms/side effects		2%	
Advice		2%	
Questions		2%	
The link/button		2%	
Interest		2%	
Humour		1%	
Countries		1%	
My house		1%	
A camera		1%	
Daily activities/Life		1%	42%
Lips/mouth		1%	
Energy		1%	
Weight		1%	
Fluid		1%	
Noise		1%	
Genes		1%	
Independence		1%	
Dignity		1%	
Death/End-of-life			22%
Illness			10%
Treatment			9%
Research			6%
Emotions			4%
Steps/precautions			3%
Aims/priorities			1%
Communication about illness			1%
Total	**100%**	**100%**	**100%**

4.4 Patient as Senser

Patient takes the role of Senser in over 15% of their overall participation within the advice data. This means that a significant amount of Patient's activity occurs within the 'internal world of the mind' (Thompson, 2004, p92) as opposed to other process types and activity which take place in the external world. Even if the Phenomenon which Patient senses exists in or is related to the outside world, the process of sensing it is one which takes place internally in the mind of the Senser. Therefore, an overview of this activity, as shown below, may provide some insight into Patient's experience of this internal world through their mental processes.

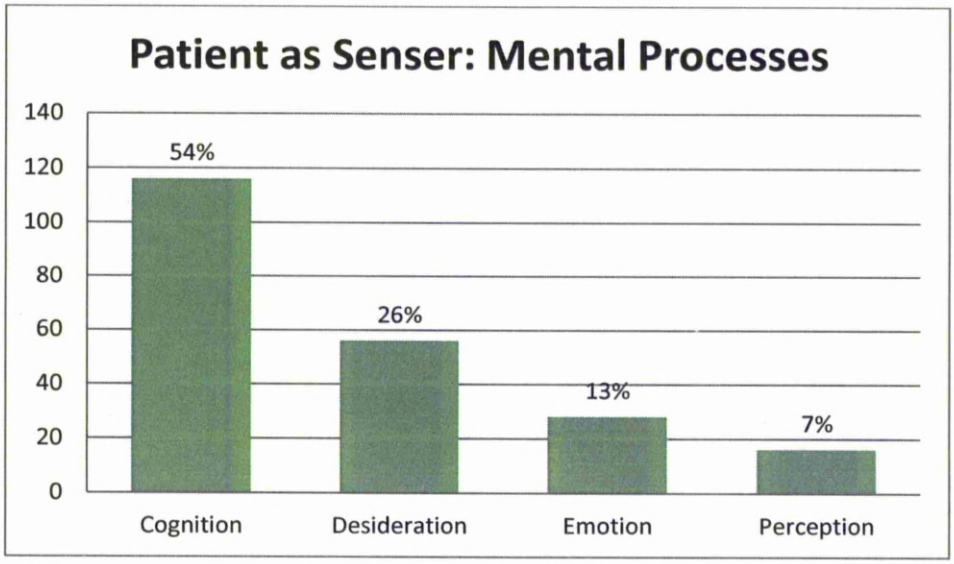


Fig. 24 Patient as Senser in Advice Data: Overview of Mental processes

The chart above shows that Patient participates as Senser in all four types of mental processes to varying degrees. The greatest area of mental activity is in processes of cognition. This is followed by desideration, emotion and perception. Each will be considered in turn, taking into account both typical processes and Phenomenon in order to explore particular transitivity templates within Patient's mental processes.

4.4.1 Processes of Cognition

Patient is involved in processes of thinking in 54% of their overall mental activity. Over half of Patient's mental activity relates to their knowledge, thoughts and beliefs. The key processes are listed in the table below in order of frequency. The most common relate to processes of discovering, thinking, knowing and feeling. The latter in these examples has a meaning akin to 'believing', rather than the more emotion based mental process or a relational process of feeling. The remaining processes occur in less than 10% of cognitive processes, although some can be seen as related to the larger and more frequent groups. For example, 'believe' can be seen as related to the larger group of belief-related processes mentioned previously.

Table 20: Patient as Senser in Processes of Cognition

Process of Cognition				**Number**	**%**
Find (out)				**23**	**20**
Think				**18**	**16**
Know	13	Don't know	5	**18**	**16**
Feel	13	Don't feel	1	**14**	**12**
Learn				**6**	**5**
Choose				**5**	**5**
Remember				**4**	**3**
Take in				**3**	**2**
Understand	2	Don't understand	1	**3**	**3**
Believe	2	Don't believe	1	**3**	**3**
Concentrate/Focus on				**3**	**2**
Decide				**3**	**2**
Consider				**2**	**2**
Anticipate/Expect				**2**	**2**
Realise				**2**	**2**
Reflect				**1**	**1**
Underestimate				**1**	**1**
Recognise				**1**	**1**
Face up to				**1**	**1**
Check				**1**	**1**
Figure out				**1**	**1**
Forget				**1**	**1**
Total				**116**	**100**

In themselves, the processes provide a certain amount of information about Patient's cognitive activity. It is also important to consider these in the context of the relevant Phenomenon as this helps to identify what it is that Patient typically discovers, thinks, knows and believes. These are given below and indicate that the context of health is significant but not exclusive.

Although technically 'think about' is followed by circumstance of Matter rather than Phenomenon, the focus here will be more generally upon the 'topic' of Patient's mental processes which may be realized as Phenomenon, expressed as a clause or a nominal group, or circumstance of Matter, typically expressed by a prepositional phrase with 'about'. For ease and economy, the term 'Phenomenon' in the following discussion will be used to cover all of these. This is in keeping with the treatment of Verbiage in verbal processes.

Table 21: Patient as Senser in Advice Data: Overview Phenomenon in Processes of Cognition

Phenomenon	**No**	**%**
Illness	18	28
Death/End-of-life	11	1
Living/Life choices	11	17
Information	11	17
Time/the future	5	8
Communication about illness	5	8
Support	3	5
Total	**64**	**100**

The most prominent Phenomenon is illness and Patient is actively involved in discovering, knowing about and understanding their illness and diagnosis, as in 'what we know about my cancer'. This area of mental activity is closely related to Patient's position as researcher in material processes and diagnosis deliverer in verbal processes and so it can be argued that Patient knowing about and understanding their illness is central to the interrelation of these three process types.

The position of the second most frequent Phenomenon is shared by three equally common areas; namely, death and end-of-life matters, living and life choices and information. Each area accounts for 17% of Phenomenon in Patient's cognitive processes and each will be considered in turn.

Regarding death and end-of-life matters as Phenomenon, these processes cover a range of mental processes from understanding, as in 'you understand what happens at this difficult time', to considering, as in 'think about how and where you would like to die' and finally deciding, as in 'you decide how you want to be treated when you are dying'. These present end-of-life decision making as a mental process based upon logic and reason, an approach which, according to Eliot and Olver (2005), is also evident within the literature.

It could also be argued that these examples form smaller links in the chain of a broader mental procedure in which Patient has to comprehend, contemplate and make choices regarding death and end-of-life matters. In this respect Patient as Senser in these cognitive processes follows a logical progression of mental activity from disclosure to decision-making. Further examples can be found below to demonstrate this pattern. Another point of possible interest as regards this group is that although all processes take place in the mind of the Patient, the further along this broader chain of mental activity Patient travels, there is a sense in which the distance between this internal mental activity and activity in the external world decreases. It could be argued that this chain of mental activity presents a progression route from thought to action and that the decisions made by Patient at the end of this chain are intended to have a direct influence upon other end-of-life processes which will take place later in the external world.

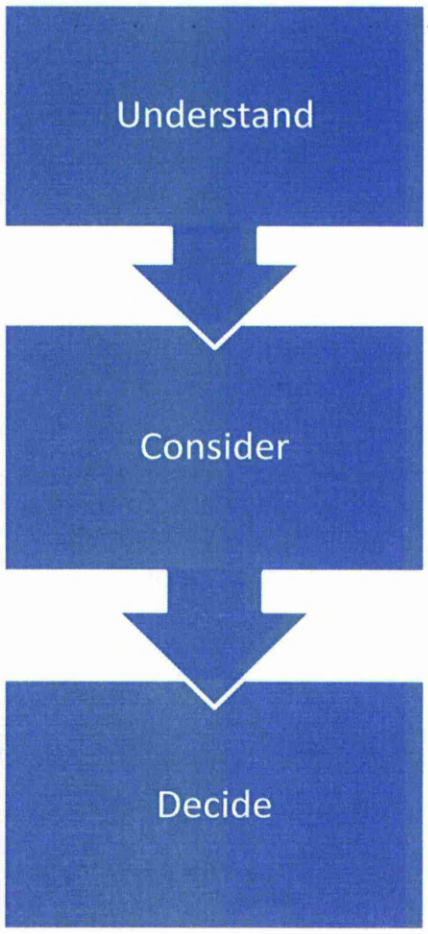


Fig. 25 Patient as Senser in Advice Data: Cognitive Processes from Disclosure to Decision-Making

However, this representation is not without its critics on the grounds that 'dominant models of medical decision making...are deficient, assuming a limited, abstracted and idealized notion of patients and families' (Eliot and Olver, 2005, p31). The result of this is that 'patients or families may be left feeling inadequate or as moral failures if they do not make the mark according to a model that makes rationality the gold standard for decision making and obliges them to live up to it' (Eliot and Olver, 2005, p31).

Somewhat in contrast to the Phenomenon of end-of-life matters, yet equally frequent, is the Phenomenon of living or life choices. Examples in this group tend to be related specifically to Patient's own life rather than life in general. They can be

divided into two main types of mental activity which involve focusing and deciding or choosing, such as 'you concentrate on living life the way you want to' and 'you decide what is important to you'. There are certain parallels with the previous topic of end-of-life choices but in this group the context is one in which Patient is actively involved in contemplating the best way to live their life and choosing which activities are priorities for them.

These examples establish Patient beyond the context of health and end-of-life matters, placing them firmly within the context of actively living. They also reinforce the importance of maintaining routine and control and creating meaning in day-to-day activities, particularly within the context of living with advanced cancer (Kennedy and Lloyd-Williams, 2009b; La Cour et al., 2009). This also suggests that Patient is not exclusively preoccupied with thoughts of illness and end-of-life matters but is actively engaged in thinking about their life and what they will do in what remains of it. This presents Patient as engaging in very deliberate consideration, decision making, choosing and prioritising such as 'choose something you think you'd like to do' and 'you decide what is important to you'. Furthermore, the numerical symmetry of life and death related Phenomena in the advice texts perhaps suggests the representation of an attempt to balance the two areas within Patient's cognitive processes.

The third type of Phenomenon at this level of frequency is cognitive activity linked to information. This group of processes relating to information can be divided into a number of subgroups based upon both the typical processes and nature of the Phenomenon. The first and most frequent of these represents the Patient as researcher in typical processes of discovering information and learning about facts such as 'You may also want to learn about the benefits you can get as a person with cancer' or 'You learn more about employment training programmes'. The next group involves Patient as Senser in mental processes of a more negative nature such as not understanding information relating to the illness and treatment as in 'any things which you don't understand' or 'anything which you forget'. Similarly there are mental processes which emphasise Patient's inability to process

information in general, such as 'you can take in only a small amount of information'. Although from the context of Patient receiving their diagnosis, it seems reasonable to assume that the information will be illness and treatment related, these examples do not explicitly mention any specific type of information but rather place more emphasis upon Patient's limitations in terms of processing that information. Finally, Patient is also involved in discovering this fact about their processing skills. These examples also overlap with mental processes of perception and Patient's involvement in both discovering and noticing their mental difficulties with absorbing new and complex information in the consultation. The overlap between processes of perception and difficulties with cognitive processing highlights the fact that patients possess a strong sense of awareness about their lack of understanding within the medical consultation (Jahad, et al., 2006).

This feature may also be seen as related to the 'non-doctor' patient (Vegni et al., 2005) who demonstrates a lack of understanding about their diagnosis, symptoms and treatment. Given that significant comprehension problems have been detected in relation to general and commonly used medical terminology for both professionals and patients alike (Hadlow and Pitts, 1991), a lack of understanding may well be greater when dealing with more complex and distressing information such as when receiving a diagnosis of terminal illness. It may also be suggestive of Patient's status as non-expert (Gülich, 2003). An example of this is 'You might also find that you can take in only a small amount of information'.

An overall pattern which emerges in the cognition-information group is the transition from Patient as active researcher to discoverer of their own limitations in mental processing of information. This represents Patient in a positive sense as mentally active and effective in finding out and learning information, but also as experiencing difficulties in the cognitive processing of information. The nature of the Phenomenon in these cases also seems to progress from the more external non-medical areas such as information about employment training programmes, to more internal and introspective areas such as Patient's own mental competence within the medical consultation. The presence of these examples within the advice

data suggests that the writers are attempting to normalise such difficulties and give Patient permission to not fully absorb, not know, not understand or not recall all the information they receive in the medical consultation. This is in contrast to previous approaches in which patient's cognitions were deemed to be of little importance (Armstrong, 1994). Moreover, Patient's cognitive difficulties as outlined in the current data have been found to be commonplace in medical consultations and these findings have been used to inform changes in Doctors' communicative skills and practices (Ley, 1988). The range of activities of Patient as Senser of information has been summarised below.

Table 22: Patient as Senser in Advice Data: Cognitive Processes processing Information

Patient as Senser as	Typical processes	Phenomenon/Information	Number
Researcher	Learn about	State benefits Employment training programmes	4
Receiver of Information	Don't understand Forget	Information about treatment	3
Receiver of Information	Can only take in	Limited information	2
Discoverer (overlapping with Perceiver)	Find that (discover)	Information processing limitations	2

A further feature of this group is the overlap between mental processes and other process types such as material processes related to researching the illness and treatment or carrying out everyday activities and verbal processes of passing on information. This overlap highlights the connections to be found between what Patient thinks and does and will be explored in more detail in the conclusion to this section.

Having considered the four most significant kinds of Phenomenon in cognitive processes, it is now possible to summarise the three remaining minor ones. Each of the three following areas fall below 10% of the overall Phenomenon in this group

and so will be briefly overviewed. The first table gives examples of each whilst the second highlights connections with other process types.

Table 23: Patient as Senser in Advice Data: Cognitive Processes and lower frequency Phenomenon

Phenomenon	Example	%
Time/the future	'people with cancer can...think about the future'	8
Communication about illness	'it is easier than you thought it would be'	8
Support/help	'think about ... counselling'	5

Table 24: Patient as Senser in Advice Data: Cognitive Processes, lower frequency Phenomenon and Process Overlaps

Phenomenon	Overlap with other process type
Time/the future	**Material** - 'think about how you want to spend your time'
Communication about illness	**Verbal** - 'You will know if you can be the one to tell them'
Support/help	**Material** - 'You may find it helpful to read some of the pieces in the your stories section' **Relational** - 'I knew that they would be supportive'

A final overview of Phenomenon in Patient's cognitive processes can be found below. This table includes all of the above Phenomenon with the addition of further areas, here labelled 'focus', which emerge from projected clauses. When projected clauses appear in mental processes, typically in processes of cognition and desideration, in the Phenomenon 'slot', they are not usually labelled as Phenomenon (Thompson, 2004) and so the decision has been taken here to refer to them as the 'focus' of Patient's mental activity.

Table 25: Patient as Senser in Advice Data: Cognitive Processes Phenomenon and Focus

Phenomenon/Focus in Processes of Cognition	Phen	Focus	Total	%
Illness	18	5	23	18
Living	11	8	19	15
Dying/End-of-life	11	7	18	14
Information	11		11	9
Communication about illness	5	6	11	9
Feelings		8	8	6
Support/help	3	4	7	5
Consciousness/the mind		6	6	5
Time/the future	5	1	6	5
Failure/poor self image		4	4	3
Mental capacity		2	2	2
Treatment		2	2	2
Dependence/giving in		2	2	2
Employers/colleagues		2	2	2
Medical research		1	1	1
Home		1	1	1
Travel		1	1	1
Total				100

Although the overall picture remains broadly the same, there are a number of slight variations which have been introduced with the addition of a wider range of areas of focus of cognitive activity. In terms of key similarities, 'illness' remains the key point of focus. However, the three areas of 'dying', 'living' and 'information' are no longer equally frequent. The first point to note is that 'living' becomes marginally more frequent than 'dying' and 'information' emerges as the least frequent of all three. Secondly, a number of new areas emerge in this analysis to a greater and lesser extent. The two most significant are 'feelings', as in 'Some people find that the emotions and feelings do not get easier to deal with' and 'the mind/consciousness', as in 'Some people feel that their soul or consciousness will live on (perhaps in a new form) or go to another place'. These examples explore meanings and 'how the person makes sense of the world' (Armstrong, 1994, p70) and represent Patient as reflecting upon their emotions, how they manage them or what they believe will happen to them after death.

A number of further areas of focus emerge such as travel, as in 'I decided I would travel to Europe'. These are few in number and many of them are tied to the context of health. For example, the effect that cancer can have upon a Patient's self-image, as in 'you feel you are a failure'. Some examples may be potentially significant in that they widen the range of focus of Patient's cognitive activity and this may in turn have some impact upon related processes. For instance, in the example 'I decided I would travel to Europe' the mental process links to the material process of travel. This represents Patient's mental activity focusing upon an activity such as travel which takes place beyond the medical context and in particular, it represents Patient engaging in activity which is not necessarily determined by the context of health, as a person like any other, undertaking non-medical activity such as travel.

A final point to mention is that grammatically negative cognitive processes, in which Patient does not know, understand or believe, should not be overlooked. Where there is a lack of understanding, this may also be significant in that unawareness, uncertainties and indecision exist in the real world and that to present advice texts without this dimension could present an unrealistic representation of Patient in the text for Patient in the real world. The presence of cognitive processes in the negative form may be significant because it normalises Patient's lack of knowledge or understanding and presents uncertainty as a typical dimension of Patient's mental processes in this context. 'Uncertainty is an important issue for chronically and terminally ill people ... The feeling of uncertainty occurs when someone does not have a cognitive framework to understand their condition or situation' (Banyard 1996, p 172). He then goes on to identify how patients tend to cope with this uncertainty; by either vigilance or avoidance and states that these 'strategies create frameworks that allow the people to explain their situation to themselves and increase their sense of personal control' (Banyard 1996, p 172).

The majority of Patient's cognitive processes are positive although there are a small number of examples of cognitive processes in the negative, as summarised below.

Table 26: Patient as Senser in Advice Data - Cognitive Processes, positive and negative

Processes of Cognition	No	%
positive	102	93
negative	8	7

Table 27: Patient as Senser in Advice Data - Cognitive Processes, positive and negative

Process of Cognition				Number	**Number**	% of total cognition	**% of Patient's total cognition**	**+ve**	**-ve**
Knowledge and Understanding									
Know	13	Don't know	5	18	**21**	16	**19**	**15 = 14%**	**6 = 5%**
Understand	2	Don't understand	1	3		3			
Opinions and Beliefs									
Feel	10	Don't feel	1	11	**14**	10	**13**	**12 = 11%**	**2 = 2%**
Believe	2	Don't believe	1	3		3			

These tables show that 7% of Patient's overall cognitive processes are in the negative and can be divided between processes related to knowledge/understanding and opinions/beliefs, comprising 5% and 2% respectively. The typical Phenomenon involved in these negative processes are summarised below and illustrate the key areas in which Patient is represented as not knowing, understanding or believing. Generally speaking, Patient emerges as not knowing or understanding their illness, followed by treatment and death, as in 'not knowing whether the cancer may come back' or 'they don't know exactly what will happen to their mind after their death'. Processes related to beliefs tend to focus upon the illness, in particular the diagnosis and self-image. Examples are 'you may not believe what is happening' and 'so don't feel you are different'.

Table 28: Phenomenon in Negative Cognitive Processes

Phenomenon	No	%
Illness	6	67
Death	1	11
Treatment	1	11
Self image	1	11
Total	**9**	**100**

To sum up Patient's cognitive processes thus far, the key types of Phenomenon have emerged as the illness, living and dying, followed by information. To some extent these can be seen as predictable focal points. However, the fact that Patient is presented as being aware of and concerned with these areas is relatively recent (Armstrong, 1994). This is part of an overdue response to recommendations as early as the 1950s on the need for cancer patients to have more awareness and information regarding their illness, treatment and prognosis (Joint National Cancer Survey Committee of the Marie Curie Memorial and the Queen's District of Nursing, 1952).

Furthermore, these processes should not necessarily be viewed in isolation and the relationship between Patient's cognitive processes and coping strategies has come to be regarded as one of significance. In particular the concept of 'cognitive control' has been found to be an important factor in the process of adjusting to cancer and how patients think and manage their thoughts about cancer and life. In fact, cognitive control has been found to have greater influence upon cancer patients' ability to accept and deal with their illness than 'informational control' (Taylor et al., 1984).

Within the biomedical model, Patient's cognitions would most likely have been restricted to knowledge of their symptoms and even this was viewed as instrumental in the doctor's compilation of Patient's medical history. In contrast to this, the current data suggests that Patient's cognitions and their understanding of their illness are now necessary for the patient themselves and this supports

previous findings that such mental processes are not only restricted to the mind of the patient, but are instrumental in how patients cope with their illness (Armstrong, 1994).

In addition to thinking about their illness, Patient is represented as focussing upon life and death in equal measure. In the case of the former, the cognitive focus upon life can be held as indicative of the transition from the biomedical to the palliative model. This is also somewhat in contrast to general perceptions about palliative medicine being concerned primarily with death. Palliative care 'is best defined by what it is not: it is not all about death and dying ... It is important to note that, almost without exception, palliative care worldwide is focused on life rather than death' (Forshaw, 2002, p147). The fact that life and living appear as Phenomenon in Patient's cognitive processes in equal measure to death as Phenomenon may be seen as evidence of this focus.

This is not to claim that the Phenomenon of death is of less importance in Patient's cognitive processes. On the contrary, it is of direct relevance to Patients' end-of-life beliefs and decisions and it can be argued that attention to how Patient views and thinks about death is essential if a 'good death' (Ellershaw and Ward, 2003) is to be achieved. The inclusion of Patients' beliefs and decisions about end-of-life and death within the advice data is of particular importance given that previous research has found there to be some disparity between the beliefs of patients and health professionals regarding what constitutes a 'good death' (Payne et al., 1996). As Forshaw (2002, p150) stresses, 'There is not one, single, fixed meaning of death, and there is not one single, fixed pathway to it'. However, it can be argued that 'a modern role of dying, which is dependent upon awareness of dying, has emerged' (Field, 1996, p225).

Finally, the cognition-information group focuses on researching information but also includes some of the more problematic aspects of mental processes within this context. In addition to representing what Patient knows and thinks, this group is also concerned with where there may be a lack of knowledge and understanding. In

effect, the advice texts are normalising the problematic aspects of certain mental processes within this context and giving Patient permission to not understand, believe or remember all the information they receive. This is particularly evident in the cognition-information group of mental processes, which can also be related to certain other process types, in this case verbal, such as 'Don't be afraid to say 'I don't know''. This uncertainty is in contrast to other medical contexts, such as medication information leaflets for patients in which the cognitive mental processes found represent patients 'as being intelligent and thus able to understand the way in which they are affected by medical conditions or medicines' (McManus, 2009, p49).

As highlighted earlier, there may be a degree of overlap between some of these cognitive processes and other process types such as material, relational and verbal. These acts of discovering, knowing and thinking are sometimes connected to or embedded within other processes. The following example shows where the mental process is embedded within the Verbiage of a verbal process, whereby the knowledge is discovered and then used by Patient for other purposes. For instance, the mental process 'what we know about my cancer' forms part of a verbal process with Patient as Sayer to their child as Receiver, as in 'I will tell you what we know about my cancer'. Such examples highlight the relationship between processes in the mind of the Patient and how they sometimes extend to reach into the external world and other entities within that world.

4.4.2 Processes of Desideration

Of the remaining processes in which Patient is Senser, 26% relate to processes of desideration. These present Patient as engaged in expressing wants, wishes and preferences with respect to certain Phenomenon in the world. The key processes of desideration are overviewed below. The dominant process type 'want' is more direct than those which follow. However, these mental processes are similar in nature.

Table 29: Patient as Senser in Advice Data – Processes of Desideration

Desideration	No	%
Want/don't want	39	69
Would like	11	20
Prefer/rather	3	5
Wish	1	2
Can't resist	1	2
Urge	1	2
Total	**56**	**100**

An additional factor is the extent to which processes of desideration express desires in the positive or the negative. This can be seen below and demonstrate that in the majority of cases, Patient expresses their positive active wishes as opposed to their wishes against anything. Examples of Patient's desideration against will be explored further when considering Phenomenon.

Table 30: Patient as Senser in Advice Data – Positive and Negative Processes of Desideration

	No	%
Positive	47	84
Negative	9	16
Total	**56**	**100**

Regarding the typical Phenomenon, it could be predicted that processes of desideration might relate to end-of-life choices and treatment and care preferences. This prediction is based upon dominant themes within the literature and the recent emphasis in medical research upon patient choice, preference and its impact upon decision-making (Townshend et al., 1990; Roberts, 1999; Wilkinson et al., 1999; Jansen et al., 2001; Department of Health, 2003; Tong et al., 2003; Ache and Wallace, 2009; Grande and Ewing, 2009; Daveson et al., 2011). Examples of these in the data are 'how and where you would like to die', 'what kind of medical care you want' and 'how you would like to be helped'. The key types of Phenomenon are outlined below.

To a large extent the key types of Phenomenon in Patient's desiderative processes in the advice data correspond to those suggested by the literature and, as table 31 shows, end-of-life matters emerge as the most frequent and care appears as the third most frequent Phenomenon. Predicted outcomes will be considered first, followed by those which were not predicted. A further feature which is common to this group is the overlap between certain types of Phenomenon. An example of this can be found in 'how you want to be treated when you are dying' in which 'treated' has been interpreted as more general than medical and therefore the focus is upon care preference and end-of-life choices. In contrast 'what kind of medical care you want if you are close to death' involves medical care/treatment and end-of-life choices. This multi-dimensional aspect of some Phenomenon has led to some examples appearing in more than one Phenomenon group simultaneously.

Table 31: Phenomenon in Processes of Desideration

Phenomenon	No	%
End-of-life choices	20	32
Living/activities	16	26
Care/support/help	10	16
Communicating about illness	9	15
Ask for/get info about illness	4	6
Treatment	2	3
Concluding activity (loose ends)	1	2
Total	**61**	**100**

The most common area of Phenomenon on Patient's desiderative processes relates to end-of-life matters. Comprising 32%, examples include 'Who would you like to have around you?', 'Where would you prefer to die?', 'How do you want to be treated by the people around you when you are dying?' and 'How would you like things around you to be as you are dying?' These examples represent Patient as expressing their desires on end-of-life choices and actively stating preferences for the circumstances of their death. This concurs with the shift within medicine to focus increasingly upon patient wishes, now regarded as making an important contribution towards a 'good death' (Ellershaw and Ward, 2003; Meeker and

Jezewski, 2005). Such research has also led to the development of models to assess and respond to patients' care preferences (Knops et al., 2005). Furthermore, Patient's processes of desideration in the advice data can be mapped onto the findings of Knops et al. (2005), whose research led to the identification of three key areas which comprise patients' care-related desires. These are: 'desire to control disease', 'desire to control death' and 'desire to control suffering' (p295). It can be argued that the examples from the data given above highlight Patient wishes regarding the 'who, where and how' of their death and concur with medical research on cancer patients' end-of-life preferences (Townsend et al., 1990; Wilkinson et al., 1999; Charlton, 2002) and the 'desire to control death' in Knops et al.'s assessment model (2005).

Patient's wishes regarding care also appear with predictable frequency, accounting for 16% of Phenomenon in desiderative processes. Although there is possible overlap at times with treatment and end-of-life choices, these examples also relate to care, help and support of a more general nature and apply to care provided by carers such as family and friends, rather than specific medical care provided by professionals. Examples of this group include 'how you would like to be helped', 'you'll be cared for in the way that you wish' and 'you may want them to support you'. These introduce the element of 'informal care' as a significant focal point of Patient wishes.

This group also reveals informal care and 'daily life' end-of-life care to be a greater focus of Patient wants than explicitly medical end-of-life care. Possible reasons for this will be explored later when considering comparisons with treatment. In the interim, the presence and frequency of this group of Phenomenon support the findings of Volker and Wu (2011) that end-of-life cancer patients report a strong desire to control 'events, choices, and personal behavior in daily life' (p1623) but desires to control other factors such as illness, treatment and the fact of dying are often expressed with less strength. However, Volker and Wu also acknowledge that although Patient control is widely accepted as instrumental in achieving a good death, the 'achievement of a death consistent with personal preferences is an

elusive outcome for most people with cancer' (Volker and Wu, 2011, p1618) due to difficulties in determining patient wishes. This may be one reason why emphasis is placed upon the role of informal carers and family members as actively involved in the provision of care and channelling of patient preferences into that care (Pierce, 1999; Steinhauser et al., 2000; Meeker and Jezewski, 2005) and achieved by actively sensing patient wishes (Thulesius et al., 2003). A further possible reason for Patient's focus upon informal care might be owing to the preference for a home death and the care requirements placed upon informal carers such as family members (Forshaw, 2002).

Additional areas of desiderative focus which can be regarded as predictable are communication and information. These can be deemed as predictable Phenomena on the basis of both the literature (Kaplowitz et al., 2002; Miyashita et al., 2006; Corli et al., 2009; Innes and Payne, 2009; Michiels et al., 2009) and their presence in the advice data within Patient's cognitive processes. Examples taken from Patient's processes of desideration are 'you want to talk about your cancer' and 'you want the answers to all of them up front'. Although there are connections with similar Phenomena in cognitive processes, there appears to be a reversal of frequency according to the type of mental activity, as shown below.

Table 32: A Comparison of Key Phenomenon in Patient's Processes of Cognition and Desideration

Process Type / Phenomenon	Cognition	Desideration
Information	17%	6%
Communication	8%	15%

In terms of unpredicted outcome, Phenomenon related to life and living accounts for 26% of Patient's processes of desideration as in, 'living life the way you want to'. This type of Phenomenon was also found to be prominent within Patient's cognitive processes whereby Patient considers how they want to live their life and several are

often combined with processes of wishing and wanting, as in 'you concentrate on living life the way you want to'.

This group also contains certain activities which can be categorised within the wider group of life and living in that they include actions which are related to Patient's wishes regarding living their life and wanting to engage in particular activities. Unlike Phenomenon such as illness, end-of-life, care and treatment, these are not explicitly governed by the context of health but are indicative of Patient's wishes for life in the time which remains. Examples of this are 'the things you really want to do', 'Is there something I want to do that I've never tried?' and 'they wanted to go to a wedding or meet their new grandchild'. It may be of interest to note that this type of Phenomenon is more common within Patient's processes of desideration than areas such as care and treatment and that within this group, and in contrast to much of the literature (Townshend, 1990; Roberts, 1999; Wilkinson et al., 1999; Jansen et al., 2001; Department of Health, 2003; Tong et al., 2003; Ache and Wallace, 2009; Grande and Ewing, 2009; Daveson et al., 2011), Patient is being represented as giving greater mental coverage to life-related wishes than illness, care or treatment related wishes.

It could be argued that this represents Patient's wants and desires as being perhaps more appropriate in the domain of living life than in the more medical domains of illness and treatment. It could also be argued that the desire to live life according to one's wishes is heightened within the medical context of terminal illness and that this desire is part of the wider process of learning to live with terminal illness whereby all activity is repositioned within a limited timescale. As Armstrong-Coster's research into patient narratives and the stages of the dying journey revealed, virtually 'no aspect of their lives would remain unaffected by the changes their diagnosis had brought about' (2004, p80). This therefore can include examples of concluding activities, or 'tying up loose ends', such as 'issues that you would like to sort out with particular people' in that these are activities which may not otherwise have been included within Patient's wishes, were it not for the influence of their context of health.

A further unpredicted pattern in the data is that treatment appears far less frequently than anticipated and as suggested by the literature (Jansen et al., 2001; Montoriet et al., 2006). However, it is worth noting that treatment accounts for 10% of Phenomenon in Patient's cognitive processes as opposed to 2% of their desiderative processes and this represents Patient as being more likely to engage in making logical cognitive decisions about treatment than expressing wishes and desires about treatment. Such a division may be indicative of more traditional and 'dominant models of medical decision making' (Eliot and Olver, 2005, p25) whereby Patient is represented making rational decisions as opposed to decision making governed by personal desire and wishes. Thus, according to Gergen's (1992) labels, Patient's mental approach to treatment can be categorised as less 'romantic' and more 'modernist'; that is, less emotional and more rational. In addition, it is also possible that treatment as Phenomenon may be more likely to appear in certain types of mental processes than others. For example processes of cognition and desideration would relate to treatment decisions and desires prior to treatment. On the other hand, processes of emotion might be more likely to relate to Patient's feelings prior to and in reaction to treatment (Armstrong-Coster, 2004).

As mentioned previously, in the advice data Patient is represented as expressing wishes regarding informal or non-medical care far more frequently than regarding treatment. It is also the case that the more frequent, informal care Phenomena of Patient's processes of desideration tend to be more ambiguous in terms of who is providing the care and that this may be less important than the type of care Patient wants. Whilst Patient is represented as permitted to want certain things related to informal care, interestingly, there is less evidence of this in the data regarding medical and treatment wishes. More importantly, this presents a representation of Patient which is incomplete when compared to certain related research findings (Jansen et al., 2001; Thulesius et al., 2003; Armstrong-Coster, 2004; Knopps et al., 2005) where patients have been found to be more involved in expressing treatment preferences.

Based upon the advice data representation of Patient wishes, it could be argued that Patient is permitted to express wishes on certain Phenomenon more than others. Additionally, it may be that in the domain of treatment, there is the expectation of greater patient adherence and compliance. Adherence can be defined as 'following the advice of health care professionals' and is considered important because, in most cases, 'medical interventions rely on patient adherence' (Abraham, 2004, p92). However, research has shown that patient adherence and compliance are often overestimated (Banyard, 1996) and in this respect, the data may present a somewhat idealised representation of Patient.

Another possible explanation as to why Patient's wishes within the more general domain of care are more apparent is that they are being represented as more appropriate. Patient may be underrepresented as expressing specific wants in the more medical domain of treatment because it may be deemed less appropriate for Patient to want or desire a particular treatment and more appropriate to accept and comply with the recommendations of medical experts. Furthermore, there is no evidence in the advice data of Patient being categorised as wanting alternative forms of treatment, possibly due to the assumption that Patient will want the conventional treatment as recommended by their medical team. This assumption of compliance regarding treatment is evident in research on Patient narratives (Armstrong-Coster, 2004) and therefore in this respect, according to the literature, the advice data presents a version of the Patient in the text akin to the patient in the world. This will later be compared to findings in the interview data in order to establish whether the patient interviews verify this finding.

It could also possibly be argued that treatment is less evident as Phenomenon in Patient's desideration because of the non-curative aspect of terminal illness. However, this goes against one of the fundamental goals of palliative medicine in which treatment is not cure-focused, as in the biomedical model, but rather it is quality-of-life focused in its endeavours to control pain, alleviate suffering and support patients in the final stages of their lives (Kübler-Ross, 1973, 1981; Banyard, 1996; Johnston, 2004a; Saunders and Baines, 1983).

Interestingly, much of the medical and sociological literature and research suggests that expressions of 'hope' are a key focus for terminally ill patients (Nekolaichuk et al., 1999; Eliot and Olver, 2002; Nekolaichuk and Bruera, 2004). However, in Patient's processes of desideration in the advice data, there are no examples of this particular mental process. This may be partly due to a particular interpretation of hope within medicine which is 'to couple hope with cure, even to equate the two' (Eliot and Olver, 2002, p179). Furthermore, within the framework of desideration, it can be argued that 'hope is the active desiring of a possible positive future outcome' (Eliot and Olver, 2002, p184) and this mental process may be more problematic within the context of terminal illness. Hope as a process of desideration for Patient may be absent in the advice data due to the very subjective and personal nature of hoping which may be regarded as an inappropriate activity on which to advise patients. However, this is not necessarily to suggest that Patient is represented as 'without hope' because hope can also be expressed as an external attribute and this can be explored when examining relational processes.

Having considered the key processes and Phenomenon in Patient's desiderative processes, there remains one final aspect to explore before concluding this group. This relates to examples of negative desideration and identifying what it is that Patient does not want. These occur in 16% of Patient's desiderative processes and as they have been stipulated within the advice data, it can be assumed that they are of some significance in terms of both the recognition of things to avoid and the permission afforded to Patient to 'not want' specific Phenomenon. These are outlined below in order of frequency, with examples from the data.

Ref	*Example*	*Type*	*Phen/Focus*
End-of-life choices: treatment, care, people			**3**
98/99*	... if you don't want to be touched or moved in any way for some time before or after death.	D	end-of-life choices/care
112*	...particular treatments that you do not want to have?	D	end-of-life choices/treatment
115*	...people you do not want around?	D	end-of-life choices/people
Communication about illness			**3**
89	... you don't want to talk about your illness.	D	to talk about illness
159/60	...you do not want to talk about your illness...	D	to talk about illness
166	...not wanting to talk is caused by depression.	D	to talk (about illness)
Information about illness			**2**
86*	Not wanting to know anything about their cancer	D C	illness/info
3	... nor may you want to know the answers to all of them up front.	D C	to know the answers to all of ?s to Doc
Daily activity			**1**
167	...you might not want to get up in the morning.	D	to get up in the morning

Fig. 26 Patient as Senser in Advice Data: Phenomenon in Processes of Negative Desideration

The first set relates to end-of-life wishes regarding the care, treatment and people which might be deemed undesirable by Patient. Such preferences inform the key goals of end-of-life care for patients regarding 'what is important to them at this time e.g. their wishes, feelings, faith, beliefs, values, organ donation' (Liverpool Care Pathway for the Dying Patient, 2011, p14) and 'your wishes about the remainder of your life, including your final days and hours' (Royal College of Nursing and Royal College of General Practitioners, 2011, p1). They are important in terms of respecting Patient's final wishes and making sure that they are treated according to and not treated against their wishes at the end of their life. The presence of wishes both 'for' and 'against' certain Phenomenon in the data construes Patient's wishes in both directions as being of importance in a way which represent the Patient and their wishes being respected until the very end in accordance with the basic premise of palliative care (Saunders, 1977). This is also in

accordance of the first of seven principles which form the basis of core competences for end of life care: 'Choices and priorities of the individual are at the centre of planning and delivery' (NHS National End of life Care Programme, 2009, p4).

In contrast, the remaining three sets may be more applicable to a context prior to end-of-life. The fact that there are more examples collectively within these sets suggests that Patient's capacity to 'not want' certain things is not restricted to an end-of-life context, but is in fact more applicable to the longer term situation of living with terminal illness. This can be summarised as shown below.

Table 33: Patient's Negative Desideration in Context of Time

Negative Desideration in context	No	%
Living with terminal illness choices	6	67
End-of-life choices	3	33

4.4.3 Processes of Emotion

The next group of mental processes are those of emotion. These account for 13% of Patient's mental processes and represent Patient as feeling and reacting to certain Phenomenon. The key processes of emotion are summarised below in order of frequency.

Table 34: Patient as Senser in Advice Data –Processes of Emotion

Emotion	No	%
Enjoy/like	8	30
Accept/come to terms with	5	18
Love/care about	4	15
Be irritated	2	8
Blame	2	8
Appreciate	1	3
Take for granted	1	3
Upset	1	3
Hurt	1	3
Fear	1	3
Worry	1	3
Concern	1	3
Total	**28**	**100**

Interestingly, there are no grammatically negative processes within this group. However, the positive and negative polarity can be examined differently in this group based upon semantic rather than grammatical grounds. The table below indicates that Patient is represented as engaging in processes of emotion which are almost twice as likely to be positive as negative. Examples of these are (positive) 'the people that you love', 'you appreciate their support' and (negative) 'they are irritated by day-to-day problems'.

Table 35: Patient as Senser in Advice Data – Positive and Negative Processes of Emotion

Emotion	No	%
Positive		**66**
Enjoy/like	8	30
Accept/come to terms with	5	18
Love/care about	4	15
Appreciate	1	3
Negative		**34**
Be irritated	2	8
Blame	2	8
Take for granted	1	3
Upset	1	3
Hurt	1	3
Fear	1	3
Worry	1	3
Concern	1	3
Total	**28**	**100**

The positive to negative ratio in Patient's processes of emotion may be somewhat indicative of the 'Emotion-Focused Approach' within a taxonomy of coping strategies which includes positive emotions and 'positive reappraisal' (de Faye et al., 2006, p242). Equally, this could be viewed as an imbalance in the advice data in favour of positive emotion as opposed to the more problematic and less positive emotions more commonly addressed within the literature such as depression, anxiety, fear and spiritual pain (Grumann and Spiegel, 2003; Johnston, 2004c; de Faye et al., 2006; Tamura et al., 2006a, 2006b; Lloyd-Williams et al., 2007). Whether or not this imbalance is replicated in the patient interview data will be revealed later when comparing both data sets. A further possible explanation is that negative emotion appears encoded within other processes such as relational processes with mental attributes, which has been explored in more detail and found to be the case when examining Patient's relational processes. Meanwhile, more can be revealed by examining the relevant Phenomenon for Patient's processes of emotion as summarised in the table below.

Table 36: Phenomenon in Processes of Emotion

Phenomenon	No	%
Activities	9	31
People	9	31
Illness	6	20
Problems	1	3
Relationships	1	3
Reactions of others	1	3
Support	1	3
The future	1	3
Emotions	1	3
Total	**30**	**100**

Two types of Phenomenon emerge as equally the most frequent; activities and people. Examples of the former group cover leisure or physical activities which generally co-occur with positive emotions such as 'to enjoy listening to music' and 'you can enjoy these fun activities'. Although negative emotion is present in this group, as in 'activities that you once took for granted', there is a greater tendency towards positive processes emotion, as shown below.

Table 37: Patient's Processes of Emotion re Leisure Activities as Phenomenon

Process	No	%	%
Enjoy	6	67	
Like	2	22	89
Take for granted	1	11	11
Total	**9**	**100**	**100**

A positive reaction to leisure activities is not particularly surprising given the nature of the Phenomenon and that these are activities which are chosen specifically because of their enjoyment inducing qualities. What is perhaps of note is that these enjoyable activities take such a prominent position within Patient's emotion and are represented as more prevalent than other Phenomena such as illness. On the one hand, these are not explicitly connected to the context of health and support the theory that finding meaning in everyday activities is of significance for cancer

patients (Kennedy and Lloyd-Williams, 2009b; La Cour et al., 2009). Equally, it could be indicative of the fear that in becoming a cancer patient, one will 'become detached and separated from ordinary 'normal' mainstream life' (Armstrong-Coster, 2004, p39). They are activities which have been re-contextualised and filtered through the experience of living with terminal illness and so may well take on a new meaning for Patient within the framework of 'living life to the full'. They also connect with some of Patients' mental activity mentioned previously such as cognitive and desiderative processes related to life choices and time, as well as material processes related to physical and leisure activities and time management.

Furthermore, this represents Patient as having the physical and emotional resources to undertake and enjoy such activities which could be regarded as somewhat prescriptive and not always appropriate for cancer patients who may be experiencing fatigue or depressive episodes. Given that these are examples of challenges which are not uncommon for cancer patients (Barraclough, 1994; Mendoza et al., 1999; Bowling, 2005; Finlay, 2005; Lloyd-Williams and Hughes, 2008), the representation of Patient being largely engaged in positive processes of emotion in relation to the Phenomenon of leisure and everyday activities could be held as an idealised representation of Patient's emotion based activity.

An equally frequent Phenomenon for Patient in processes of emotion relates to people. This group relates primarily to family and friends, although there are some examples in which the Patient is both Senser and Phenomenon as Patient reacts reflexively. Examples include 'you still care about them', 'I will always love you' and 'you may blame yourself for your illness'.

A greater proportion of the processes can be categorised as positive emotion, although the margin between positive and negative emotion is slightly narrower than for the previous group of Phenomenon related to 'activities'. Overall, there is greater emphasis upon positive emotions of love and care for Others. To some extent it is unlikely that advice texts for patients would place undue emphasis upon Patient's negative emotions towards Others as this would be both inappropriate

and quite possibly inaccurate. However, the fact remains that, given its very personal and subjective nature, such positive emotion from Patient towards Others may not automatically have appeared in the data. The choice to include it may be attributed to the writers' assumption that it is necessary for Patient to have both physical and emotional proximity to Others and to have concluded 'unfinished business' as prerequisites for a good death (Ellershaw and Ward, 2003).

The only negative emotion expressed is that of 'blame' which appears as Patient's reaction both to other people and themselves in relation to illness causation. It may be worth noting that within the literature, there is a greater tendency for cancer patients to blame themselves for their illness, rather than others (Tamura et al., 2006b) although the data presents both as being equally likely Phenomena for Patient to blame for their illness. An overview of the key processes of emotion directed at people can be found below.

Table 38: Patient's Processes of Emotion re People as Phenomenon

Process	No	%	%
Love	2	28	72
Care (about)	2	28	
Like	1	16	
Blame	2	28	28

The next type of Phenomenon is 'illness' which accounts for 20% of Patient's emotion processes. The typical processes can be found below and it becomes surprisingly apparent that the majority of Patient's emotional reactions to their illness, symptoms and side effects involve processes of acceptance, as in 'trying to come to terms with their illness' or 'you...accept having to rest, or the loss of activities'. Patient's less accepting reaction to their illness is that of 'concern' and relates to how their illness will impact upon their relationships, rather than direct concern about the illness itself.

Table 39: Patient's Processes of Emotion re Illness as Phenomenon

Process	No	%	%
Accept	2	33	83
Come to terms with	2	33	
To cope with	1	17	
Be concerned	1	17	17

The greater positive to negative ratio of emotion is evident within this group also. Although it could be the case that 'coping' is interpreted as less positive than 'enjoying', it is arguably more positive than 'not coping'. Therefore, it appears that this is emerging as a common pattern relating to Phenomenon groups in Patient's processes of emotion, even in cases where the Phenomenon might not in itself be viewed as positive, such as 'illness'. A positive emotional response to illness in terms of 'coping' could also be construed as indicative of a form of adherence rather than non-compliance. As with all key findings, it will later be verified whether this pattern of positive reaction to illness is also evident in the patient interview data.

A final point regarding illness as Phenomenon for Patient as Senser is that it was found to be prominent in cognition but not desideration and this corresponds with the hypothesis that certain Phenomenon are more likely to co-occur with certain process types, as shown below. This will be examined more comprehensively across Phenomenon and process types at the close of this chapter.

Table 40: A Comparison of Illness as Phenomenon in Processes of Cognition, Desideration and Emotion

Process / Type / Phenomenon	Cognition	Desideration	Emotion
Illness	28%	0%	20%

The remaining examples of processes of emotion appear with minor frequency and have been summarised below with examples, ranging from Patient's positive to more negative reactions.

+ve	*Ref*	*Example*	*Type*	*Phen/Focus*
	Positive 33%			
	6/7	there isn't a right or wrong way to cope with the emotions a diagnosis can cause	E	emotions
	155	You appreciate their support...	E	support
	Negative 67%			
	21	... they are less irritated by day-to-day problems.	E	problems
	25/26+	Others may be concerned about ... their relationships.	E	relationships
- ve	98	...the reactions of others upset or hurt you...	E	reactions of others
	215	...you may...fear for your future	E	the future

Fig. 27 Patient as Senser in Advice Data: Minor Phenomena in Processes of Emotion

4.4.4 Processes of Perception

The final category of Patient as Senser concerns processes of perception, which comprise 7% of Patient's mental processes. These are summarised in the tables below according to process and polarity, followed by an overview of the key Phenomenon related to these processes.

Table 41: Patient as Senser in Advice Data –Processes of Perception

Perception	**No**	**%**
Find (that)	6	37
Hear/not hear	5	31
See	2	13
Feel	2	13
Not recognise	1	6
Total	**16**	**100**

Table 42: Patient as Senser in Advice Data - Perception Processes, positive and negative

Processes of Perception	No	%
positive	13	81
negative	6	9

Table 43: Patient as Senser in Advice Data – Phenomenon in Processes of Perception

Phenomenon	No	%
Side effects	3	20
Information load	3	20
Hallucinations	2	12
Family and friends/people	2	12
An urge to talk	2	12
Conversation/sound (words)	2	12
Patient information Guide	1	6
Stories about treatment	1	6
Total	**16**	**100**

The most frequent type of Phenomenon relates to the perception of side effects and symptoms and could have been predicted based on patterns in other patient advice texts (Driscoll, 2000) but appears with far lower frequency in the current data. Examples include both positive and negative side effects, such as side effects of the illness and treatment, as in 'you may find that you easily become very tired, and that your body is no longer as strong and reliable as it once was', as well as the side effects of physical exercise, as in 'people find they have more energy when they take part in physical activities'. In both these cases 'find' relates to the noticing of physical changes and so has been analysed as perception rather than another type of mental process. This construes Patient as actively monitoring their symptoms, side effects and physical changes, thereby performing tasks typically within the remit of the 'doctor-patient'.

With equal frequency to side effects is the Phenomenon of information load whereby Patient notices their own inability to absorb information, as in 'You might

also find that you can take in only a small amount of information'. Chronologically, this follows on directly from the point of diagnosis and represents entering into a state of reduced perception.

The following four types of Phenomenon all appear with equal frequency and will be dealt with briefly. They can be broadly categorised as conversation and sound, the urge to talk, people and hallucinations. The first subset relates to the point of diagnosis disclosure and Patient's inability, rather than ability, to perceive what is being said to them. This precedes cognitive processes in that the message is not perceptively detected, as opposed to being detected and then later not comprehended. Examples of this relate to the situation following the point where Patient has perceived and understood the initial diagnosis but from then on, is unable to perceive any further details. Examples of this type of 'perception shutdown' are 'They did not hear the rest of the conversation' and when the doctor is talking, 'I couldn't hear any sound coming out'.

Post diagnosis, the Phenomenon evident is an urge to talk, as in 'People feel an overwhelming urge to discuss it with everyone' in which Patient perceives and recognises this urge which then requires 'finding an outlet' for their emotions (Armstrong-Coster, 2004, p59). Interestingly, this stage represents a significant period of time between diagnosis and death and yet one in which, despite its duration, there are very few processes of perception.

Processes of perception next become evident in the final stages of life. In this period, Patient is engaged in the perception of Others as they sense people around them or do not, as the case may be. These examples relate to the final stages of life where Patient's perception functioning may be diminished and so even if they cannot see their loved ones, 'you will be able to hear them' or 'you may not recognise your family or friends'. Coupled with this is the Phenomenon of 'things which are not there', labelled 'hallucinations'. These are sights and sounds which Patient sees or hears at a stage when their perception skills start to malfunction

and can be seen as part of a wider process of Patient's 'gradual deterioration of functional status' (Ellershaw and Ward, 2003, p31).

A comparison of these processes raises an unusual inversion of perception in that there may be a lack of Patient perception of certain Phenomenon which do exist, such as the doctor's words, whilst certain Phenomenon which do not exist are perceived by Patient. This presents a disparity between what Patient as Senser would ordinarily do and what they are doing or not doing in the context of health. It also suggests that at two key points in time; diagnosis and death, some of Patient's mental processes are characterised by 'perceptive dissonance'.

A further point of note is that these processes of perception and related Phenomenon can be traced chronologically and they represent a cross section of Patient's passage from the point of diagnosis disclosure to the final stages of life. This has been summarised in the figure below.

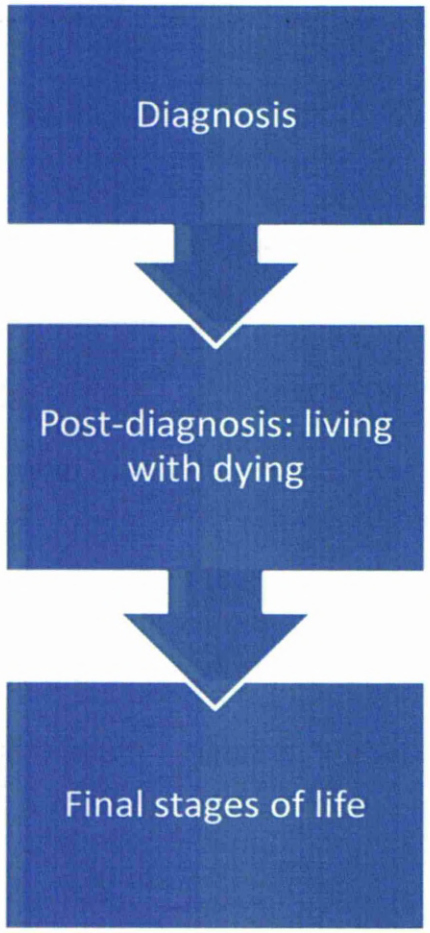


Fig. 28 Patient as Senser in Advice Data: Processes of Perception from Disclosure to Final Stages of Life

Two final areas of Phenomenon are patient information guide and stories about treatment. Both are given equal weighting as sources and Phenomena to be perceived by Patient which is possibly significant as they represent the 'voice of medicine' and the voice of the life world' (Mishler, 1984, p103-104). However, it should be mentioned that they are presented as equal in number only and when each Phenomenon is viewed in context, the treatment of each cannot be regarded as equal. For example, 'see the patient information guide for details of helpful books' compared to 'stories you hear about people being treated years ago will be out of date' presents the voice of medicine as being a useful source of more up-to-date, reliable and helpful information than outmoded anecdotal stories from patients about treatment.

An overview of Patient's mental processes and distribution of Phenomena can be found in table 44 and this provides a profile of Patient's mental activity. One general feature of this profile is that there is a significant amount of Phenomena variation according to the type of mental process. In fact, no Phenomenon appears to relate to all four types and only two types of Phenomenon can be found in three of the four process types; namely, living/activities and care/support/help. Of these two areas, there is greater emphasis upon living in Patient's mental activity and it is of note that living as Phenomenon takes precedence over illness in the mind of the Patient. The degree of diversity of Phenomenon will also be considered when examining the patient interview data.

Table 44: A Comparison of Key Phenomena in Mental Processes

Process / Type / Phenomenon	Cognition	Desideration	Emotion	Perception
Illness	28%		20%	
Death/End-of-life	17%	32%		
Living/activities	17%	26%	30%	
Information	17%			
Time/the Future	8%		3%	
Communication about illness	8%	15%		
Care/Support/Help	5%	16%	3%	
Request for information		6%		
Treatment		3%		
Concluding activity (loose ends)		2%		
People			30%	12%
Problems			4%	
Relationships			4%	
Reactions of Others			3%	
Emotions			3%	
Side effects/symptoms				20%
Information load				20%
Hallucinations				12%
An urge to talk				12%
Conversation/Sounds				12%
Patient information Guide				6%
Stories about treatment				6%

In places this summary conforms to predicted patterns but, as mentioned previously, some unexpected patterns have emerged. For example, there are no expressions of 'hope', fear of death or faith beliefs. All of these are considered to be of significance for terminally ill patients according to the literature and yet do not appear in the advice data.

One possible reason for their absence here is that much of the literature is based upon Patient interviews and so it may be more likely to find similar themes in that data set. A further possibility is that certain areas have not been included on the basis of being possibly inappropriate within the remit of advising terminally ill patients. For instance, it may be inappropriate to advise on an issue as personal as faith matters, particularly given that it may not be relevant to all patients. There is very little perception and monitoring of symptoms compared to other illnesses, with little focus upon areas which are significant in terminal illness such as pain and fatigue. However, it is worth verifying whether these points emerge within other process types in the advice data, such as attributive processes and also whether they are evident in the patient interview data.

To summarise Patient as Senser overall, although in terms of grammatical analysis these mental processes are distinct from others which happen in the external world, that is not to say that they bear no connection to the external world. Within health psychology, although some examples of terminology are used slightly differently, the relationship between the two realms is evident. This is that mental processes can be regarded as influential upon other types of processes and in this respect, boundaries between types of mental processes and other types of processes can become blurred. As Forshaw argues,

> If someone thinks something, then they tend to believe it. If they perceive something a certain way, they are likely to think along the lines of that perception, and have faith in their perception. If they believe something, their thoughts will often spring from that belief. Perceptions, beliefs and cognitions may all lead to one thing: behaviour (2002, p 24).

Mental processes offer vital information in the attempt to discover how Patient makes sense of and reacts to their experience of living with terminal illness. Although this activity takes place within Patient's mind rather than the external world, this is not to say that there is no relationship between the two. As Armstrong argues, patient meanings are central to the social experience of illness because 'Society is not 'out there' but inside people; the social reaction can only therefore be studied by exploring this internalized social world' (1994, p70).

4.5 Patient as Sayer in Advice Data

Patient takes the role of Sayer in slightly over 13% of their overall participation and these processes involve the passing on of messages or information. Both the typical Receivers and types of messages will be outlined in this section.

4.5.1 Patient as Sayer: Receivers

Of the 180 processes within this group, 164 examples found involve a Receiver or addressee as opposed to only 16 instances where no obvious Receiver or addressee is mentioned. This means that Patient's messages are, in over 90% of cases, directed specifically towards other people rather than simply being messages or statements made without intended recipients. Two types of recipients can be found in the data. The first is the explicit Receiver and is more easily identified, as in 'talk to your GP', where it is clear that the Receiver is Doctor. The second type of recipient is an understood addressee which is not explicitly stated but from the context it is clear that they are the intended recipient of the message. Examples of this are 'it is helpful to explain what is wrong' or 'there is no easy way of saying it'. In the first example, it can be argued that ordinarily when things are explained, they are generally explained to someone and that from the context of this example, it is evident that the explanation of the Patient's illness is being passed from parent to child. Similarly, but perhaps less obviously, the second example is also directed to the Patient's child and again the context and heading make it clear that this example could be rephrased as 'there is no easy way of saying *to your child* that you have cancer'. Both types have been included because for the purposes of this study, it was felt that whether the Receiver is explicitly stated or not may be less important than whether it is clear from the context who the intended Receiver is.

A further point to mention is that some verbal processes involve more than one receiver simultaneously, as in 'Talking things through with a friend or a professionally trained person'. This example involves two distinctly different

Receivers, both of which have been considered within the relevant categories which follow. An overview of the main Receivers can be found below.

Table 45: Receivers to Patient as Sayer in Advice Data

Entity	Explicit Receiver	Understood Addressee	Total No	%
Other	74	51	**125**	**66**
Professionals	41	17	**58**	**30**
Patient	5	2	**7**	**4**
Total	120	70	**190**	**100**

The main Receivers to Patient's Sayer are Others, health or other professionals and Patient. By far the largest category of Receivers is Other and this group includes three sub-categories. The first relates specifically to children, as in 'Talking to children about your cancer' or 'explain to your children that you will tell them about your health and about any changes'. The second category of Other is more general and relates to family and friends. Examples of this group are 'discuss with your family and friends where you would like to be looked after' or 'talk about end-of-life choices with your loved ones.' Although it could be argued that children, by definition, belong within the broader category of friends and family, it was felt that children merited specific attention. This is partly on the basis that they are stipulated as a particular kind of Receiver within the advice data, and this will be returned to when considering the nature of the messages Patient passes on to their children. A further reason for this choice is simply the frequency with which they appear and that as the largest single type of Receiver, they merit individual attention within their own category.

The final and least frequent type of Other is from the context of work rather than family and relates to Patient's employer and colleagues, as in 'Let your boss and co-workers know if, and when, you want to talk about your cancer'. This final category,

although minor, may be of some significance in that it takes the role of Patient as Sayer outside of both the traditional and reconfigured medical gaze. The former considers Patient as the site of illness, where the latter, emerging from the current data, considers Patient beyond being the site of illness but also as a person with a family, all of whom are involved in the illness. The significance of Patient's representation in an employment based context is that it places them beyond the scope of illness/medicine and the family/home and extends Patient's parameters to the world of work. The figures for each of the three types of Others as Receivers can be found below.

Table 46: Overview of Other as Receivers to Patient as Sayer in Advice Data

Other as Receiver		%
Other (children) = 73	**125**	59
Other (friends and family) = 44		35
Other (employer/colleagues) = 8		6
		100

The second largest group of Receivers can be labelled as 'Professionals'. This group consists mainly of Doctors, or other health professionals such as nurses subsumed within that category. The smaller group of professionals includes entities such as social workers, counsellors and undertakers. The scores and percentages for both are given below.

Table 47: Overview of Professionals as Receivers to Patient as Sayer in Advice Data

Professional as Receiver		Percentage
Doctor = 42	**58**	72
Other support = 16		28

The final type of Receiver to Patient's Sayer is also Patient. These instances are few and so can be briefly summarised in terms of Sayer, Receiver and the message. In some cases, these are reflexive processes in which the Patient is engaged in a dialogue with him or herself. A typical example of this group is to 'ask yourself if you would like some help with this issue' in which Patient is simultaneously Sayer and Receiver, conducting an internal dialogue regarding how they respond to and cope with their illness. In another type of example they are advised that they may or should not 'blame yourself' for their illness. These may be regarded as connected with the moral aspect of medical information exchange (Maynard, 1998) in that they are examples of Patient voicing a more moral response to their illness and its cause.

Other examples of Patient as Receiver to Patient's Sayer involve other cancer Patients as listeners. An example of this is 'talking to someone who has been through the same experience'. These Receivers are presented as appropriate listeners due to their first-hand experience, knowledge and understanding of Patient's illness. On the basis of their own experience, it could be argued that a fellow cancer Patient as Receiver offers Patient as Sayer an understanding and hearing which other types of Receivers are not necessarily able to provide. The appearance of these examples within the data supports the view that 'the so-called non-expert is an expert in at least *one* respect – his or her own illness' (Gülich, 2003, p248). It may be of some significance that such examples seem to recognise the expertise of the Patient as Receiver in this type of exchange. It can also be argued that the Patient as both Sayer and Receiver arrangement is an example of how the Patient is becoming professionalised into a new type of role which extends far beyond the traditional role of the patient to include activity which is more typical of the doctor within a consultation. Processes in which Patient as Sayer speaks to Patient as appropriate listener bear some similarity to the professional doctor-patient exchange and support the claim that identities and relationships vary depending upon the type of consultation (Strong and Davies, 1978).

4.5.2 Key Receivers and Message Topics

More can be revealed about emerging patterns within verbal processes involving Patient as Sayer by examining the nature of the messages communicated. These have been labelled using the approach used when also considering patient as Receiver. This involves identifying topics which are explicitly mentioned and those which are recoverable from context. This approach also incorporates Glaser and Strauss' 'Grounded Theory' (1968) whereby data is analysed without the existence of previously established categories but categories of themes or topics are generated by the data itself during the analytical process.

The topics will be considered both overall and, where relevant, in relation to specific Receivers. The topic may be realised by a clause or a nominal group, included within the category of Verbiage, or by a prepositional phrase. In addition, in the case of verbal processes, the topic may only be inferred from the context. Given that children constitute the largest single groups of Receivers, these will be considered first. The main topics of verbal processes involving Patient as Sayer to children as Receiver are given below.

Children as Receiver

Table 48: Overview of Topics for Patient as Sayer and Children as Receiver in Advice Data

Topic	No	%
Illness	50	48
Communication	40	39
Treatment	7	7
Assurance / Emotional support (child's emotions)	2	4
Patient's emotions	2	
Instructions to act (tidy up etc)	2	2

Clearly the main topic emerges as illness. This may be predictable given that these texts are aimed at cancer patients but it is perhaps noteworthy that illness makes up a significant proportion of the verbal processes in which Patient is Sayer, as opposed to simply Receiver. This suggests that in addition to more typical material processes involving their illness such as 'going to hospital' and 'having treatment', relational processes such as 'having cancer' or 'being terminally ill' or receiving verbal information about cancer, Patient is also actively involved in passing on information about their illness and treatment. This inclination to talk about the illness is perhaps evidence of a wider change within medical practice in which, having previously been considered somewhat unmentionable subjects, cancer and terminal illness have become more openly discussed (Brewin, 1977; Novack et al., 1979; Saunders and Baines, 1983; Innes and Payne, 2009). This change is particularly marked in the context of disclosing a cancer diagnosis and talking about terminal illness to children where research suggests that adult avoidance of this topic in relation to children is not uncommon (Barnes et al., 2002).

In contrast and possibly in response to this, some of the texts in this set are entirely devoted to or have significant sections advising Patient on talking to their children about their illness such as 'Talking to children about your cancer' and 'Tell them what has happened, such as some details about the cancer'. These provide guidelines on and evidence of recent efforts to change the status of cancer and terminal illness from unmentionable to openly discussable, in order to address the needs of and alleviate anxiety levels for both the cancer Patient and their children so that they might better cope with the illness (Kennedy and Lloyd-Williams 2009a; 2009b).

These examples suggest a significant change in attitudes to the illness and how it is dealt with by the Patient in the family. In itself this is important because it is a clear example of the reconfiguration of the medical gaze whereby the Patient is not merely the site of the illness, but a person with a family who are also involved in the process of dealing with the illness. Moreover, verbal processes emerge as instrumental in the family coping with the illness as in 'let the children know that

you have plenty of time to discuss the situation with them' and 'it is helpful to explain what is wrong'. These can be regarded as examples in accordance with a multi-disciplinary team approach to palliative care (Johnston, 2004a), in which the Patient and their family are essential components.

Another important aspect of this particular topic is that it focuses upon the Patient's role as Sayer in giving the news of their diagnosis to their children and then explaining the nature of the illness and treatment to them. Again this is of interest because it places the Patient in a role which is more typical of the Doctor and provides evidence of the Patient taking on a new role whereby they become an intermediary between Doctor and Other in the passing on of medical information and Patient is thereby 'assigned two roles in the system of information exchange' (Adelswärd and Sachs, 2003, p136-137). This will be explored further in connection with the next most common topic of verbal processes involving Patient as Sayer.
In tandem with diagnosis disclosure is the topic of communication. In these examples Patient is presented as following specific guidelines on how to communicate the news of their diagnosis to the child and provide a satisfactory explanation to them of the illness and treatment. This is related to but differs from the previous topic in that it focuses on the method of communication rather than the content and is regarded as equally crucial to an effective approach to palliative care which includes the family (Johnston, 2004a; Kennedy and Lloyd-Williams, 2009a). In particular, the methods and effectiveness of communication are regarded as crucial to how children are able to cope with their parents' illness and avail themselves of the support offered to them (Kennedy and Lloyd-Williams, 2009a; 2009b).

Examples of this are 'Who should tell my children?', 'When should I tell my children?' and 'how to talk about cancer with children'. These particular examples summarise the 'who, when and how' of Patient performing diagnosis disclosure for their children. In addition 'Why should my children be told?' addresses the rationale for disclosure and the reasons given in the data often mirror those given in the literature (Brewin, 1977; Johnston, 2004b; Grabiak et al., 2007; Kennedy and

Lloyd-Williams, 2009a; 2009b). Examples of this can be found in 'Openness can help all of you to feel closer', 'Children can feel isolated if they are not told', 'Not knowing things can make them feel anxious' and 'Children who know the situation can be a comfort to you.'

Of these four factors, the category of 'how' entails more detailed instructions which can be mapped on to guidelines given to trainee medical practitioners (Johnston, 2004b), as shown below:

Guidelines for Doctors	Advice for Patient as Sayer
1. Establish what the person already knows and understands about the illness	Ask them what they think cancer is
2. Establish what the person wants to know about the illness	You don't have to tell everything at the same time
3. If they want to know more, it should be honest and clear	Don't lie Talk in a language and at a level that each child understands
4. Allow time and silence so that news can sink in	Let the children know that you have plenty of time to discuss the situation with them
5. Respond to their reaction and give further information as required	It is very important to answer any questions that they ask at this time
6. Plan treatment and arrange follow up interview	Explain what will happen next, such as how it will be treated

Fig. 29 The Six Stages of Breaking Bad News (adapted from Johnston, 2004b)

Further examples appear within the advice data which also match some of the finer details within the six stages and these may also be worth highlighting in order to demonstrate the degree of overlap between the Doctor and Patient in delivering bad news. For example, in relation to stage 3 the Doctor should 'avoid euphemism' (Johnston, 2004b, p97), which can be paired with advice to the Patient to 'Just say

'cancer''. Another example is related to guidelines to the Doctor on disclosing information as dictated by the Receiver whereby 'what is said should be given at the person's pace' (Faulkner et al., 1994, p150). This can be coupled with advice to Patient as Sayer such as 'You don't have to tell everything at the same time' and 'Be willing to talk whenever your child asks questions or seems concerned about your condition.' Both of these tie in with the principles and practice of 'gradual disclosure' (Diamond, 2001) applied by doctors to patients, now being appropriated by Patient to their children.

Following on from the two major topics of messages, there is also some focus upon the topic of treatment. To some extent this could be included within illness but as it is specified a number of times, has been categorised separately. In connection with the illness-related messages, these can be regarded as follow-up or parallel processes in which Patient, having received information about treatment, is involved in communicating that information to Others. Examples are 'you can explain the treatment and how it is given' and 'Explain how it will be treated'. There is also some overlap with advice on how to communicate with the inclusion of a 'warning shot' (Faulkner et al., 1994, p147), usually employed when delivering the diagnosis, being incorporated to preface information about treatment. This can be found in 'It can be best to give children warning that something is about to happen, such as a scan or treatment, shortly beforehand'. Furthermore, Patient's efforts to update their children on treatment can be seen as crucial to the relationship between three key factors; namely access to information, inclusion and children's ability to cope with the illness (Helseth and Ulfsaet, 2003; Grabiak et al., 2007; Kennedy and Lloyd-Williams, 2009a; 2009b).

Two further topic areas relate to the emotions of both Patient and their children in which both entities are given equal coverage in examples such as 'you can say you may feel more sad than normal, or may be more easily irritated' and 'Ask them if they are worried about anything in particular' or 'Assure them they will still be loved and cared for'. These indicate the importance of Patient explaining their own emotions to their child (Kennedy and Lloyd-Williams, 2009b) as well as responding

to the child's emotional needs and response to the illness (Forrest et al, 2006; Grabiak, et al., 2007).

It may therefore be claimed that open communication, regarding facts, emotions and decisions, emerges as fundamental to the family's ability to cope with the challenges presented by the context of health. Examples to support this can be found in the advice data such as 'Let them know how the situation affects your feelings and emotions as well as giving factual information about the cancer' and 'explain to your children that you will tell them about your health and about any changes'. These comply with the research findings of interviews with families affected by cancer in which Kennedy and Lloyd-Williams (2009a, p154) stress that 'communication involves more than the giving of factual information, and includes aspects such as support and feelings of involvement.'

The final area relates to Patient giving instructions to children to carry out domestic tasks such as 'she told me to pick up my toys'. These are perhaps significant because they are somewhat removed from the context of health and place the Sayer and Receiver as ordinary parent and child, passing on everyday routine messages rather than discussing illness. This places both Patient and child within their normal domestic routine. To some extent these may contribute towards 'maintaining normality' (Kennedy and Lloyd-Williams, 2009b, p889) for the Sayer and Receiver because they relate to domestic routine.

To conclude this section, the key topics in verbal processes for Patient as Sayer to children as Receiver relate to the illness, communication, treatment, emotions and instructions. Furthermore, the themes which emerge from the advice data bear some similarity to those mentioned by children of parents with cancer when interviewed about their perceptions of cancer. 'Themes included children's awareness of cancer before their mother's illness, how children learnt of their mother's diagnosis, their reactions to this news, their reactions to their mother's treatment, and their expressed need for information' (Forrest et al., 2006, p999). Therefore, certain parallels can be drawn between the topics which have emerged

from a transitivity analysis of the advice data and those which have emerged from research within the wider medical field.

Family and Friends as Receiver

Table 49: Overview of Topics for Patient as Sayer and Friends and Family as Receiver in Advice Data

Topic	No	%
Illness	21	43
Feelings	12	25
Communication	6	12
End-of-life choices	5	10
Treatment/care	4	8
Social invitation	1	2
Total	**49**	**100**

The table above lists the key topics for Patient as Sayer to family and friends. In terms of the topics included there are some similarities to those for children as Receiver, such as illness, feelings, communication and treatment. One point to note is that there is greater coverage of talking about feelings which may be because Patient is more likely to share their feelings with fellow adults. This is of potential interest because it is akin to the coping mechanism of their children who report needing to talk about their emotional response to the illness but not wanting to burden their parents. Therefore they choose to and find it easier to talk to their friends about the illness (Kennedy and Lloyd-Williams, 2009b). Examples including 'telling them how you feel' and 'discussing their worries and fears with the people closest to them' show Patient behaving in a similar way. Although communication appears as a topic for friends and family, it is not as prominent as for children. Examples such as 'tell the people around you that you don't want to talk about your illness' are linked more to Patient's communication preferences rather than explicit guidelines on how to communicate with their family and friends.

One topic which does appear with friends and family as Receiver but not directly with children is that of end-of-life choices. In some cases the role of Receiver is

shared with Doctor or other professionals, as in 'let them know if you need special practices to be done or if you don't want to be touched or moved in any way for some time before or after death'. In other cases such as 'talk about end-of-life choices with your loved ones', children could be included although they are not explicitly mentioned as in the previous Receiver group. This topic is slightly more frequent than treatment and suggests that Patient as Sayer should make these choices known in order to ensure that their wishes are followed. It is also indicative of a wider move towards examining end-of-life choices and decision making and what constitutes a 'good death'. In some cases, the views of medical practitioners and related professionals such as counsellors have been explored (Pugh et al., 2009; Rushton et al., 2009), while others have examined the views of both practitioners and patients (Ellershaw, 2002; 2003; Ellershaw and Wilkinson, 2003). They also demonstrate that the discussion on end-of-life choices is one Patient conducts with their friends and family as well as their Doctor.

Of the remaining topics, treatment is a further example of Patient expressing preferences to Others, as in 'saying how you would like to be helped' or discussing care-related decisions such as 'discuss with your family and friends where you would like to be looked after'. Similarly to certain processes involving children, these tie in with the notion of effective palliative care which involves good communication between the Patient and those closest to them (Johnston, 2004a).

Employer/Colleagues as Receiver

Table 50: Overview of Topics for Patient as Sayer and Employer/Colleagues as Receiver in Advice Data

Topic	No	%
Illness	6	60
Work	2	20
Training	1	10
Communication	1	10
Total	**10**	**100**

The table above shows key topics for Patient as Sayer to employer and colleagues. In common with all other entities so far, the topic of illness is most frequent, as in 'you talk about your cancer'. The other recurring topic of communication appears, as in 'Let your boss and co-workers know if, and when, you want to talk about your cancer' and relates specifically to Patient's communication preferences. Two topics which are unique to this set of Receivers are work and training, as in 'Ask about training programs'. These tend to relate to how Patient's illness or treatment may or may not affect their ability to do their job or the need to change their role within work. This places the Patient within a distinctly less medically related arena in a broader social context where their position is not necessarily determined by their illness, where they have functioned in a rather different role prior to the onset of illness compared to their current patient role. Therefore, whilst small in number, these instances serve to position the Patient as a person in the world of work rather than simply a patient in a medical context or a patient with a family and family life which is being affected by the illness.

Overall, the proximity of Patient's activity as Sayer to that of Doctor indicates that they are being advised to follow guidelines similar to those set out for Doctors, passing on information about their illness and treatment to their children, friends, family and colleagues. This suggests that there is a sense in which the Patient is being trained as a specific type of Patient who at times takes on a role more traditionally associated with Doctor. This type of 'doctor- patient' differs from that already identified as performing lay diagnosis which is more commonly placed within the medical consultation (Sarangi, 2001; Shaw and Baker, 2004). The type of 'doctor-patient' emerging from the current advice data acts outside of the traditional medical consultation, operating instead within their own 'consultations' with children, friends, family, employers and colleagues. To some extent they are a patient hybrid of the 'doctor-patient' and what Vegni et al. (2005) refer to as the 'educator-doctor'. The connection between this hybrid role, Patient's verbal activity and other processes and process types, such as Patient as Receiver, as Actor in material research and Senser in mental learning about the illness, will be further explored later.

Professionals as Receiver

Table 51: Overview of Topics for Patient as Sayer and Professionals as Receiver in Advice Data

Topic	No	%
Illness	31	42
Treatment	18	25
Feelings	12	16
Help/care	4	6
Daily life	2	3
Laws	2	3
End-of-life choices	2	3
Work	1	1
Communication	1	1
Total	**73**	**100**

As mentioned previously, Doctor and other health professionals form over 70% of the Receivers in this group, the remainder being professionals such as social workers, counsellors and undertakers. Given the nature of the Receivers, it is not surprising that the dominant topic is again illness. Previous research into advice leaflets presented similar findings and the two illness-related areas in which Patient is Sayer to Doctor's Receiver were identified as information about illness and symptoms and requests for information on the same (Driscoll, 2000). In the current study a similar pattern emerges with verbal processes from Patient to Doctor. However, there is less emphasis on reporting symptoms, as in 'Let your doctors and nurses know if you have pain when you do this activity' and far greater emphasis upon requesting information, as in 'people ask about having cancer' and 'the questions you will want to ask your local medical team'. Another area which receives more attention than symptoms is the process of clarifying information through the process of talking, as in 'You can talk things through with a nurse' and 'you would like to talk to someone outside your own friends and family'. The greater focus on requesting information and clarification can perhaps be attributed to the nature and complexity of the diagnosis and treatment of terminal cancer, as opposed to another context of health. These examples can also be related to stage

5 of the process of breaking bad news, in particular the Doctor's role to respond to Patient's reaction and give further information as required (Johnston, 2004b).

The topic of illness is followed by and closely connected to treatment in examples such as 'talk to your doctor about your treatment'. In several cases, the topic of illness and treatment are both relevant and there is also a degree of overlap with the third most common topic of feelings. Examples of this combination can be found in 'talk over the situation with a trained counsellor or psychologist' and 'one person told us "It wasn't until a long time afterwards that I realised the stress of my cancer had made me depressed and very tearful"'. Both suggest that the topic of emotions as outlined previously in relation to Others as Receivers extends beyond Patient's personal relationships to those with Professionals as Receiver. It also touches upon the significance of this being incorporated in the Doctor-Patient relationship, in particular doctor-patient communication (Deans, 2004) which will be explored further when considering the reversal of Sayer to Receiver roles.

Having considered the three major topics of illness, treatment and feelings, certain minor topics can be summarised. These include help/support/care, daily life, laws, work and communication. Areas such as help/support, end-of-life choices and communication have appeared with Other as Receiver and are reasonably predictable based upon the type of Receiver, professionally engaged in supporting and communicating with Patient. These are more clearly aligned to the context of health, as in 'asking whether there is a doctor, nurse, therapist or social worker who can help you'.

In contrast, Patient's verbal processes related to the topics of daily life, work and laws place Patient beyond the medical gaze, in everyday, legal and employment contexts, representing the person in the wider world beyond the patient in the world of illness and medicine. For example, one topic area to emerge is social invitation, as in 'I ask my daughters over for a meal'. Whilst this is a minor topic in terms of coverage, its significance may be less so because it represents the Patient issuing a social invitation. Its significance lies in its position outside the medical

gaze, within the domain of domestic normality. As such it represents the Patient's maintenance of normality and routine. This was discussed earlier as an important coping mechanism for children (Kennedy and Lloyd-Williams, 2009b) and its presence here suggests that it may also perform a similar function for Patient and friends and family.

Patient as Sayer: No Receiver

In addition to verbal processes directed at a particular Receiver, there are a small number of instances in which no particular explicit Receiver appears but Patient is Sayer and certain topics can be identified. These can be overviewed in order to consider topic overlap or divergence in comparison with topics directed at specific Receivers. The topics without Receivers can be seen below.

Table 52: Overview of Topics for Patient as Sayer with no Receiver in Advice Data

Topic	No	%
Communication	6	29
Feelings	5	24
Illness	4	24
Death	4	19
Positive use of time	2	9

In general there is more overlap than divergence. Of the five main topics of verbal messages identified, four can be found in verbal processes with Receivers. The only topic to be exclusive to this group is that of death whereby Patients relate experiences of death on the basis of near death experiences, as in 'others describe sinking or floating into nothingness'. Although it could be argued that the topic here is near death rather than actual death, from the context it is clear that these examples are included as reports from other Patients expressing what the Patient who is the addressee of the text might expect and what the experience of death might entail.

The following table provides a more comprehensive overview of topics for Patient as Sayer in relation to verbal processes with all Receivers and no Receiver.

Table 53: Receivers and Topics to Patient as Sayer in Advice Data

Receiver / Topic	Children	Friends & Family	Employers & Colleagues	Professionals	Patient	No Receiver	**Total**
Illness	50	21	6	31	3	4	**115**
Communication	40	6	1	1		6	**54**
Feelings	4	12		12	2	5	**35**
Treatment	7	4		14			**25**
End-of-life choices		5		2			**7**
Help/care/support				4	2		**6**
Death						4	**4**
Positive use of time					1	2	**3**
Work			2	1			**3**
Instructions	2						**2**
Daily life				2			**2**
Laws				2			**2**
Social invitation		1					**1**
Training			1				**1**

Table 53 gives an overview of the distribution of topics for Patient as Sayer overall and per Receiver and shows that only the topic of illness is common amongst all Receivers and is the most common topic overall. There is also some indication that the topic focus shifts depending upon who the Receiver of the message is. For example, certain topics are exclusive to certain Receivers, such as in 'instructions to act' to children and 'training' to employers and colleagues. In a similar vein, the topic of 'death' emerges as particular to Patient as Sayer without Receiver.

Finally, a brief comparison can be made between key topics of which Patient is the Receiver and those of which they are also Sayer. As the figure below shows, where there is some uniformity in terms of the frequency of messages to and from Patient in relation to the key topics of treatment and feelings, there is a significant difference between the frequency of illness related messages for Patient. Surprisingly, there are far more instances of this topic for Patient as Sayer compared to Patient as Receiver. This indicates that in the case of verbal processes, the topic input is lower than topic output. It also supports the hypothesis that the increased topic output on illness is perhaps generated from other non-verbal activity such as Patient's illness-related research activity carried out via material and mental processes, establishing a new research-based type of 'doctor-patient'.

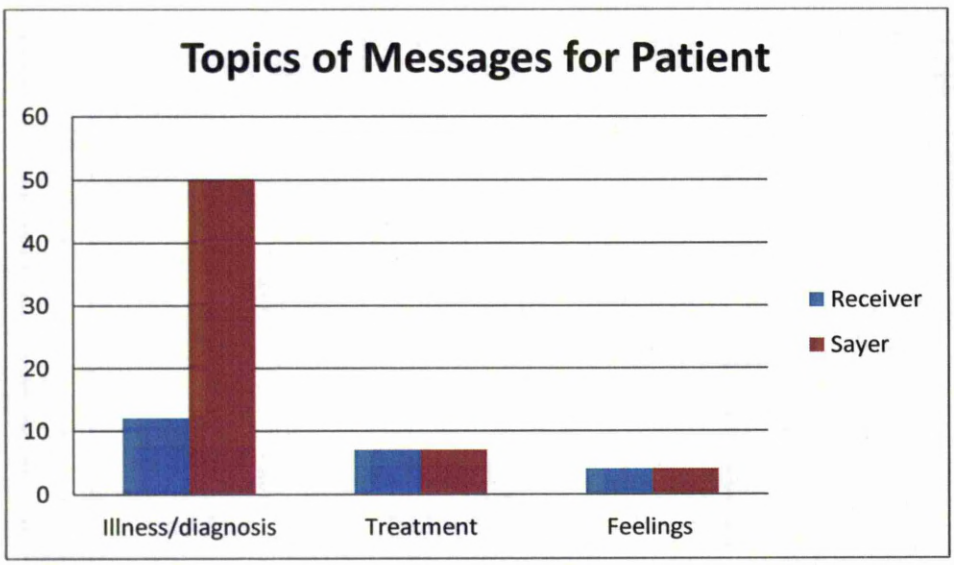


Fig. 30 Patient as Receiver and Sayer: Key Topics of Messages

4.6 Patient as Actor + inanimate Goal in Advice Data

The following role of Patient as Actor + inanimate Goal forms over 10% of Patient's appearances in the advice data and is an example of a role of higher dynamic value, within the range of 'medium' dynamism according to the 'high, medium, low' scale outlined previously.

There are a total of 150 examples in this group and it may be worth distinguishing between the types of material process and the key Goals in these processes. Firstly, all examples belong in this category by virtue of having a Goal and therefore all can be automatically categorised as 'non-middle' processes (Berry, 1977) which involve both Actor and Goal. Furthermore, all are carried out by a conscious Actor, Patient, as opposed to a non-conscious Actor such as the illness. It is also possible to further distinguish between 'intentional' or 'involuntary' material processes, found to be 93% and 7% respectively.

By far the more dominant type of material process for Patient as Actor + inanimate Goal is in intentional material processes, which will now be overviewed. Whilst these examples are numerous, it is not the case that each can be easily categorised. In fact, whilst some patterns have become apparent, it is also the case that a number of examples do not appear to obviously fall into the main categories which have emerged. However, before considering the exceptions and variants, it is important to first consider where some identifiable patterns can be discerned. The table below lists some of the more frequent process types which have been grouped in terms of related meaning. Those in bold indicate sets which each comprise over 20% of the more frequent process types for Patient as Actor + inanimate Goal.

Patient as Actor + Inanimate Goal in Intentional Material Processes

Typical Processes:

use/spend/ take
find out/find/read/look at/research
set/make/organise/reorganise
make/take/leave/make up/choose
make/write
get (obtain)
contact
put/sort

Fig. 31 Patient as Actor + Inanimate Goal in Advice Data: typical intentional processes

Initially this list may appear to reveal little about the representation of Patient in the advice data and requires more attention to context and information regarding the related Goals in order to create a more detailed impression. The preliminary outline which can be offered, on the basis of this list and related Goals, is of certain types of activity which Patient as Actor + inanimate Goal engages in. In this respect, Patient begins to emerge as a person who uses and utilises things, is involved in active research and is proactively planning, organising, making choices, creating written records and legal documents, obtaining things which are regarded as necessary or an entitlement, contacting organisations and organising their belongings. If these types of material processes are taken as the key, but not exclusive activities in which Patient intentionally acts upon inanimate Goals, a possible overview emerges as shown in table 54 below.

Table 54: Key Intentional Material Process Types for Patient as Actor + Inanimate Goal in Advice Data

Process	No	%
Use	22	27
Find out	19	24
Organise	8	10
Choose	8	10
Write	7	9
Obtain	6	8
Contact	5	6
Sort	5	6
Total	**80**	**100**

Clearly, this overview remains somewhat general and the key process types in themselves reveal only a partial impression of Patient as Actor. Nevertheless, it may be of some interest that, based on the more frequent processes, few obvious examples of medical processes can be identified at this level. However, the context of health and illness, although rarely explicitly stated in this group, is not insignificant given that the predominant activities relate quite clearly to those which are often associated with and typically carried out or encountered in an end-of-life context. This will hopefully become more evident when considering the nature of Patient's inanimate Goals.

General comparisons can also be made with Patient as Actor + animate Goal, where the focus is predominantly upon helping, protecting, supporting and taking care of Others. In the case of Patient as Actor + inanimate Goal, there appears to be more involvement in differing but not unrelated processes. There still appears to be a focus upon doing things which may be helpful to Others, albeit indirectly. However, rather than other people being the actual Goals of such activity, Patient is involved in carrying out activities such as making use of support, finding out about their illness, making schedules and rotas for other people and taking care of legal affairs, administration and their personal belongings. It could be argued that the majority of these activities can have a positive and helpful impact upon Others as well as the

Patient and in this respect, Patient's activity + inanimate Goal is not entirely unconnected to their activity as Actor + inanimate Goal.

Conversely, there are some respects in which Patient's activity as Actor + inanimate Goal differs from Actor + animate Goal. The first and most fundamental of these relates to frequency in that Patient as Actor is more than ten times more likely to act upon an inanimate Goal than an animate one. Understandably, when dealing with a significantly larger group of data, there tends to be a wider range of processes and Goals and attempts to categorise varied findings can become more complex. To some extent it can be easier to detect and establish patterns, where they exist, within a smaller data set. This has led to certain challenges which have necessitated a third level in approach to the analysis of this particular set in order to attempt to gain a more thorough inspection of Patient's participation within this group. The reasons and approach will be outlined below.

Of the 150 examples within this set, just over half can be categorised within the more frequent process types outlined previously. Firstly, in order to better understand the participation of Patient as Actor in this group more clearly, it is necessary to look at the processes in conjunction with key Goals. The emerging Goals are shown in figure 32 below and include all Goals which appear on a minimum of three occasions. Those which appear less frequently have not qualified for more detailed attention at this stage. Collectively, the more frequent Goals account for almost 80% of Patient's inanimate Goals.

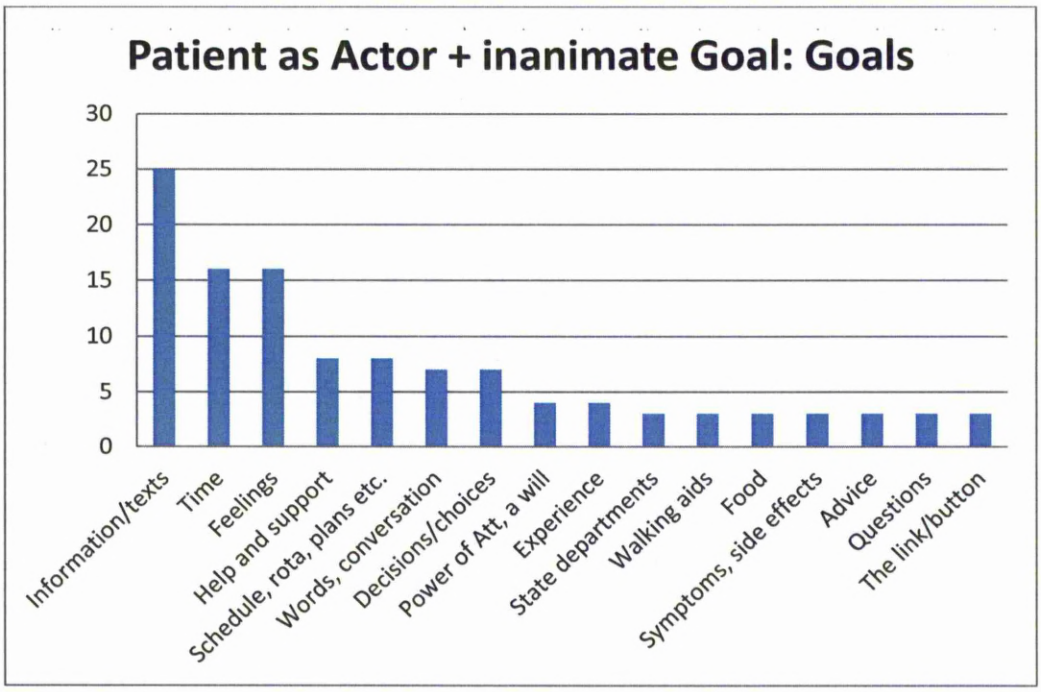


Fig.32 Goals for Patient as Actor + Inanimate Goal in Advice Data

The predominant Goals appear to be cancer-related information and texts, time and feelings, which collectively comprise 43% of this set. As these comprise the most frequent types of Goals, they will be considered in more detail. The largest and first of these to be considered is that of information and texts with the related processes given in the table below.

Table 55: Processes for Patient as Actor + Inanimate information based Goals: Material Processes of Intention

Process	No	%
Find out, find, get	11	44
Look at, read	5	20
Give, send	4	16
Write	3	12
Take in, use	2	8
Total	**25**	**100**

Evidently, the main activity for Patient with regard to information based Goals relate to 'finding' information related to cancer or cancer treatment. Following on from this are activities of more focused investigation, 'looking at' and 'reading' specific texts or sections of recommended texts. When these two groups are combined to form over 60% of this group, the picture emerges of a Patient who is actively involved in researching and understanding their illness and treatment. This key finding represents Patient as medical researcher, appropriating a role which has traditionally been within the doctor's domain. It therefore represents Patient in a very different light from that previously projected by the biomedical model with doctor as the source of medical knowledge and patient as mostly uninformed or the passive recipient of knowledge selected and passed on from the doctor at their discretion. This challenges previously established notions of 'medical knowledge, which only a profession can have' (Nightingale, 1980, pv). Furthermore, the high frequency of Patient's material processes as active researcher can also be linked directly to their mental processes of cognition in which a similar pattern has been established whereby Patient is learning about and understanding their illness.

The next key activity relates to the passing on of some of this information and occurs in a slightly smaller proportion compared to the closer, more focused investigation. Incidentally, these examples of 'giving' and 'sending' information or contributions could possibly be allocated to the fourth category of Patient's inanimate Goals; words and conversations. However, it was felt that these examples were more closely related to the wider process of finding and passing on information as opposed to the smaller category of advice on specific communication and conversation skills.

'Writing' or 'writing down' form the next group and these are associated with stories or family history. Finally, 8% of this group involves processes of 'taking in' or absorbing and 'using' the information about cancer. It could also be suggested that the 'giving' and 'sending' mentioned previously can be regarded as examples of 'using' this information once the Patient has researched, found, examined and processed it. Frequency aside, these specific processes can be reordered to offer a

logical and reasonably comprehensive overview of information gathering, processing and redistribution so that Patient and their significant Others are appropriately and sufficiently informed about the context of health, illness and treatment. Based on these transitivity patterns, it can be broadly summarised in the chart below.

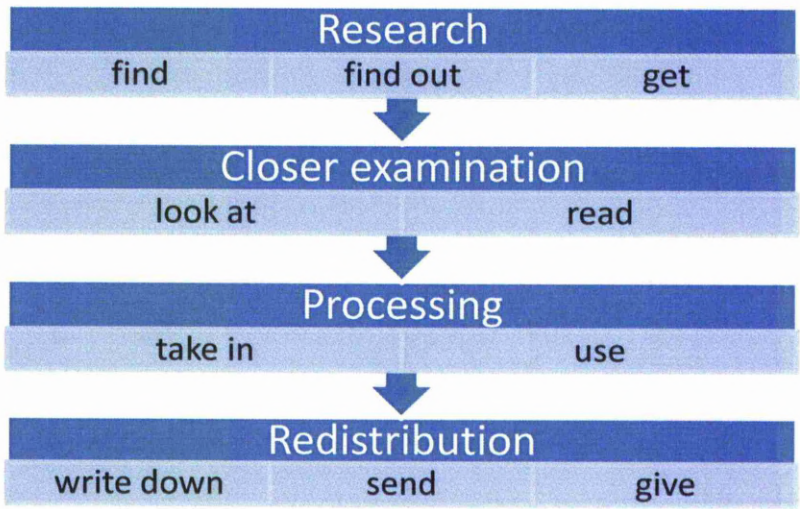


Fig. 33 Patient as Actor + Inanimate information based Goals: overall process of information gathering and distribution (Material Processes of Intention).

It may also be worth highlighting the fact that this path of activity may be considered unexpected and, at the very least, reflects a less passive role than the traditional information-receiver role assigned to patients. This is reinforced further by Patient's related activity as Senser in cognitive mental processes, in which they are actively engaged in understanding, learning, thinking, knowing and becoming more informed about their illness. The combined effect of these material and mental processes is the transformation of Patient into medical researcher, who becomes 'the knowing Patient', who then takes on the Doctor's mantle of disseminating their medical knowledge to others. This therefore confirms an emerging role of some significance for Patient, representing them, as it does, in a radically different role.

In over half of these instances Goals are referred to in general terms as 'information' and the remaining instances, comprising 45%, are given as more

specific sources of information or texts, as summarised in the table below. Almost invariably the nature of this information is related to the context of health and illness, with two possible exceptions as shown in table 57. The topics of travel and family history do not seem overtly connected to the context of health and illness. However, on closer inspection, both are presented as actions to be prioritised and carried out before death within the wider framework of terminal illness.

Table 56: Typical Goals for Patient as Actor + Inanimate information based Goals

Goal	No	%
Information	12	55
Specific sources of information: stories, contributions, first person accounts, quotations, books (about cancer), previous/current issues, sections, family history	10	45
Total	**22**	**100**

Table 57: Patient as Actor + Inanimate information based Goals: Topics of Information

Topics	No	%
Cancer/illness	19	76
Counselling	4	16
Travel	1	4
Family history	1	4
Total	**25**	**100**

To sum up, when Patient is acting upon inanimate Goals, a priority as set by the advice data seems to be activity related to finding, consuming, studying and disseminating information to Others. This information is usually related to Patient's illness and treatment. It is also possible that the same activities could have been encoded as mental processes of discovering or verbal processes of telling Others this information. However, the fact remains that although related activity appears in mental and verbal processes, it is also encoded here in material processes, affording Patient greater dynamism than the roles of Senser and Sayer.

The next two categories of inanimate Goal are equally frequent with both time and feelings appearing 16 times and each comprising 12% of Patient's total inanimate Goals. Both will now be considered in more detail. Regarding time, Patient is actively engaged in organising, setting aside and taking time in order to carry out further actions. In some cases this can be directly linked to the context of health and illness when it relates to taking time off work for health reasons. More usually, however, Patient is responsible for allocating time so that activities can be carried out. These activities, which may be regarded as priorities, include completing legal paperwork, organising affairs and belongings and can be categorised as end-of-life administration. It also includes allocating time for activities of a more medical nature such as recovering, an emotional nature such as accepting the end of life, a verbal nature such as explaining the situation to others and a more social nature such as spending time with others. Many of these further activity types, embedded within the use of time at the end of life, will be considered in further detail when looking at common themes and overtones of other process types. Although varied in nature, all of these 'priority' activities share the common prerequisite that time needs to be found and afforded in order to achieve these things. A general impression from this group is that time as Goal is analogous to a kind of currency which is being distributed and expended with consideration for a rather specific set of requirements to be met within a limited timescale.

Equally frequent is the appearance of feelings as Goal. Similarly to information as Goal, in most cases these Goals are referred to quite generally as simply 'feelings' or 'emotions' but over 30% of these Goals are given as specific feelings such as fear, worries, concerns, anxiety and pleasure. It can also be argued that in the majority of these specific cases, the feelings are of a more negative and less desirable nature. There is also some variation in the types of activities carried out in relation to these Goals which can be summarised below.

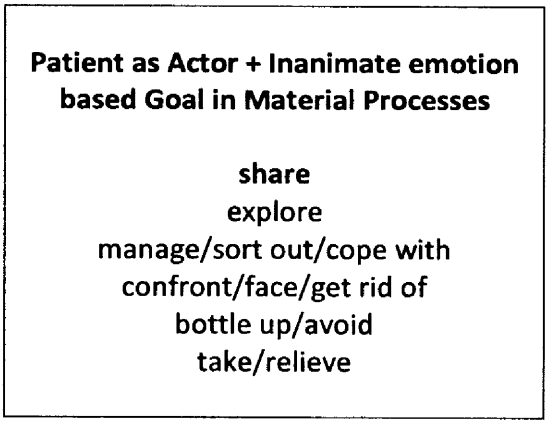


Fig. 34 Patient as Actor + Inanimate Goal in Advice Data: typical processes for emotion based Goals (Material Processes of Intention)

The most common activity in this group relates to sharing and exploring feelings and emotions. This then extends to actions such as managing feelings and emotions, confronting or eradicating them, avoiding or bottling them up. The final subset can be regarded as less neutral and more obviously positive as they relate to activity such as taking pleasure and relieving anxiety. To some extent this group can generally be regarded as a list of recommendations on how best to deal with feelings and emotions; what to do and not do. In this respect, they can be categorised and summarised slightly more delicately in the following figures. It may be of some significance that the results in this group connect with mental processes of emotion in a similar manner to the previous group with information based Goals relating to mental processes of cognition. This suggests that there is a certain emphasis on the mental realm being construed in material terms, in a way which represents Patient as actively engaged in the more dynamic processes of 'doing' with related stimulus such as information or feelings, rather than thinking or feeling.

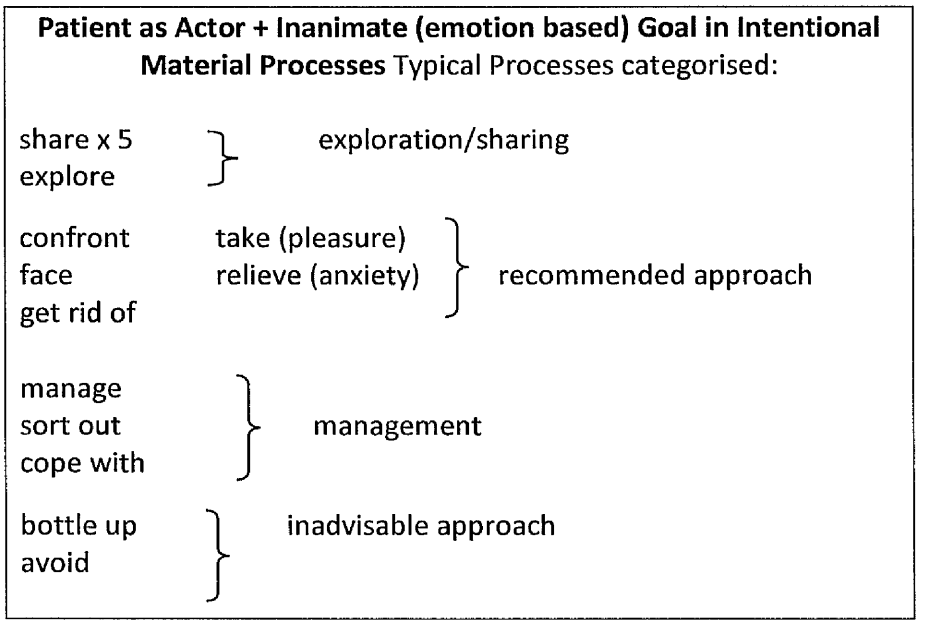


Fig. 35 Patient as Actor + Inanimate Goal: categories of typical processes for emotion based Goals (Material Processes of Intention)

Table 58: Types of Activity for Patient as Actor +Inanimate (emotion based) Goals

Types of Activity	No	%
Sharing/exploration	6	37
Recommended approach	5	31
Management	3	19
Inadvisable approach	2	13
Total	**16**	**100**

Overall, it can be argued that all of the types of activity mentioned above constitute advice on dealing with feelings and emotions. Some can be classed as very general and more neutral, whilst others are more specific with more overtly positive or negative connotations. A common point in relation to all the examples in this group is that although Patient is acting upon inanimate Goals of an emotional nature, these have been encoded in material rather than mental or relational processes. This is also one of the larger categories of inanimate Goals for Patient as Actor in

the Advice data and presents an identifiable group of processes which are material in nature but have overtones of other process types. This will be explored further as similar patterns emerge.

Having examined key processes and Goals within the larger category of processes in which Patient acts intentionally, those which do not fall inside this group should not be overlooked. The lesser of the two material process types in the advice data was found to be involuntary processes with the main processes for Patient as Actor + inanimate Goal in involuntary processes in the table below.

Table 59: Involuntary Material Process Types for Patient as Actor + Inanimate Goal in Advice Data

Processes	No	%
Make/produce	3	30
Lose	3	30
Use	2	20
Absorb	1	10
Inherit	1	10
Total	**16**	**100**

This overview indicates that Patient as Actor is equally involved in processes of production and loss, followed by use. The two lowest frequency types relate to absorbing and inheriting. In addition to the process types, some information regarding the inanimate Goals in these involuntary processes is needed to provide a more complete impression of this set. The specific inanimate Goals upon which Patient acts involuntarily are listed below.

Table 60: Goals in Involuntary Material Processes for Patient as Actor + Inanimate Goal in Advice Data

Goals	No	%
Food and drink	3	28
Energy	1	9
Weight	1	9
Fluid	1	9
Noise	1	9
Genes	1	9
Interest	1	9
Independence	1	9
Dignity	1	9
Total	**11**	**100**

This presents what appears to be a diverse set of inanimate Goals upon which Patient acts in involuntary processes, with only one Goal type which appears with noticeable frequency. Despite this, certain subtle patterns can be seen to emerge even within such a small set. Firstly Patient as Actor uses food and drink and in all cases it is 'the body' of the Patient which is referred to. Patient, or a part of Patient, is also involved in making or producing energy, fluid and noise. In contrast to more productive processes, Patient is also involved in losing weight, interest, independence and dignity. Based on this, albeit small, sample of processes in which Patient acts upon an inanimate Goal involuntarily it is possible to detect a sense in which several of these processes and Goals can be said to belong within a corporeal and physical nature once the Goal is taken into account. Those which cannot be categorised in this way, relate to more abstract Goals such as interest, independence and dignity.

Whilst it could be argued that some of these processes when examined from a general perspective might be categorised as intentional, it is important not to overlook the context in which they appear which suggests that in these instances they are involuntary. For example, the process of losing weight can be intentional if the doer is consciously making an effort to do so. If, however, this is as a result of chemical changes in the body, it would be difficult to categorise this as intentional.

Furthermore, in all cases these are processes of 'supervention' in that they happen involuntarily but involve an animate Actor. Finally, to conclude this set, it is also the case that all the above involuntary examples can be linked to the context of health and occur within the medical gaze.

Given that so much Patient activity is within the context of health and illness, one reasonable expectation might have been that more obviously 'medical' processes and Goals would have been found. Although explicitly medical processes and Goals do not emerge as predominant, they are apparent. Some have been included within previous sections of the discussion providing the process type or Goal fell within the earlier categories. However, this may not be the case for all examples and given the framework of these advice texts, it may also be worth considering examples of physical and medical activity, as summarised below. The following section is a summary based on all the relevant inanimate Goals from which certain general patterns have emerged.

Patient as Actor + Inanimate Goals in Physical/Medical Processes	
Processes	**Goals**
Use	Food
Eat	Food
Make	Energy
Save	Energy
Lose	Weight
Absorb	Food and drink
Use	Food and drink
Moisten	Lips
Moisten	Mouth
Produce	Fluid
Make	A noise
Make	A lump
Take	Medicine
Get rid of	Cancer
Control	Pain
Deal with	Medical problems
Bring to attention	Signs and symptoms
Prevent	Side effects
Control	Side effects

Fig. 36 Patient as Actor + Inanimate Goal in Advice Data: physical/medical processes and Goals

A cluster of physical and medical activity is evident when examining process and Goals together, with less than 13% of the total processes involving Patient as Actor + inanimate Goal identified as clearly medical. This suggests that in this set of texts, which aim to advise readers and Patients on living with terminal cancer, there are fewer examples of obviously medical processes than might have been anticipated. Moreover, despite the fact that most processes in this group appear to fall broadly within the context of health and illness, there are fewer overtly medical processes than would have been likely according the biomedical model and more traditional representations of Patient.

Having considered typical processes and Goals for Patient in this group, there is one distinction which should finally be addressed. Various types of Goals have been presented and the distinction between 'transformative' and 'creative' Goals also merits some attention. This divides Goals into those which are merely acted upon by the Actor and those that are created by the Actor and considers how the Actor and process impact upon the Goal. In contrast to Patient's participation as Actor + animate Goal, where all Goals were found to be transformative, there is some evidence of creative inanimate Goals. In this respect it could be argued that Patient acts upon inanimate Goals in a more creative manner than upon animate Goals. The proportion of creative to transformative Goals is given below and the following table provides an overview of key processes relating to creative inanimate Goals upon which Patient acts. Those in bold occur with greater frequency.

Table 61: Goal Types for Patient as Actor + Inanimate Goal

Goal Types	No	%
Transformative	129	86
Creative	21	14

Patient as Actor + Inanimate Creative Goals	
Processes	**Goals**
Make	**A will**
Make	**Plans**
Write	**Stories**
Write down	Questions
Prepare	Questions
Write	An advance decision (advanced directive)
Write	A lasting power of attorney
Write down	Your family history
Set	A schedule
Organise	A rota
Set	Goals
Make	A lump
Make	Energy
Produce	Fluid
Make	A noise
Make	A joke
Create	An environment

Fig. 37 Patient as Actor + Inanimate Creative Goals in Advice Data

Table 61 shows that whilst 86% of Goals are transformative, 14% are creative and that the ratio of creative-transformative Goals is slightly greater than the ratio of involuntary-intentional processes mentioned previously. This suggests an increased dynamic value for Patient from Actor in involuntary material process, which is often Goal-like, to increased participation as Actor in creative material processes in which they create the Goal. The key areas which emerge as Patient's creative Goals relate to creating documents, stories and questions, making plans and having Goals of a more physical or physiological nature. These can be regrouped by both types of activity or themes and frequency, as shown in the table below.

Patient as Actor + Inanimate Creative Goals	
Processes	**Goals**
Make	**A will**
Write	An advance decision (advanced directive)
Write	A lasting power of attorney
Write	**Stories**
Write down	Your family history
Write down	Questions
Prepare	Questions
Make	**Plans**
Set	A schedule
Organise	A rota
Set	Goals
Make	A lump
Make	Energy
Produce	Fluid
Make	A noise

Fig. 38 Patient as Actor + Inanimate Creative Goals in Advice Data – Regrouped by theme

As with earlier sets, the connection between these processes and Goals and the context of health is evident, even if not as obvious as in the case of physiological Goals. For instance, the legal documents created are presented as end-of-life administrative tasks to be carried out. Texts referred to as 'stories' relate to Patient's stories about their experience which can be made available to other Patients, whilst 'family history' is created for Others as part of the legacy Patient will leave them. Similarly, 'questions' are invariably questions about the illness and treatment. The final area of Goals relates to two different aspects of making plans. The first is within the context of making a rota or schedule for Others so that everyday tasks can be carried out with their help. In this respect it relates to Patient reorganising his/her life to facilitate help given by Others and accommodate a loss of independence caused by their illness. The second aspect relates to making plans or setting goals and aims. This set stresses the importance of creating plans in order to have something to focus on and look forward to. However, set against the

backdrop of terminal illness, this is presented as a coping strategy for Patient and when this aspect of forward planning appears elsewhere, such as in the set of schedule, rota and plan based processes and Goals, it also involves revising or abandoning plans which may no longer be realisable within the context of health.

To summarise Patient's participation in the advice data as Actor acting upon inanimate Goals, the following observations can be made. Similarly to Patient's activity with animate Goals, the majority of processes are intentional and transformative. The frequency of these processes with inanimate Goals is greater and the range of processes and Goals, as detailed above, is far wider. This can be summarised in the table below.

Material Process Type	**Typical processes**	**Goals**
Intentional/Transformative	use, spend, take, find out, find, read, look at, research, set, make, (re)organise, make, leave, make up, choose , write, get (obtain), contact, put, sort	Information/texts, time, feelings, help, plans, conversations, decisions, a will, experience, state departments, walking aids, food, symptoms, advice, questions, link/button
Involuntary	make, produce, lose, use, absorb, inherit	food/drink, energy, weight, fluid, noise, genes, interest, independence, dignity
Creative	make, create, produce, write (down), prepare, set, organise	documents, stories, questions, plans and Goals of a more physical or physiological nature

Fig. 39 Overview of Patient's Participation as Actor + Inanimate Goal in Advice Data

Although wide ranging, this group is not disparate. Commonly occurring clusters of examples emerge, such as activity relating to organising end-of-life affairs, carrying out research, dealing with feelings and communicating with Others. These all appear to be framed within the context of health and terminal illness, although the connection is often more understated than in examples of overtly medical activity. For example, 'making a will' or 'using walking aids' are not obviously health related

in the same way that 'losing weight' is, yet both processes appear to be as a consequence of or secondary to the context of health and so can be seen as intrinsically linked to Patient's terminal illness. There is some clearly medical activity but this does not dominate and so it can be argued that there is a greater tendency towards implicit connections with the context of health. A further point to note is that the range of processes and Goals in this group is such that potential overtones of other process types are not uncommon. In particular this relates to material processes with mental and verbal overtones and the implications of this, particularly connections with mental processes, have been previously explored when considering Patient as Senser. Finally, this set introduces a new but not entirely surprising element which relates to Patient as reader of the advice text, being given instructions on how to navigate their way around the website and how or where to access sections, links and so on. This representation makes certain assumptions about Patient as one who turns to the internet as a source of medical advice.

To conclude this section so far, it can be argued that it offers Patient helpful guidelines on carrying out actions which are designed to have a positive impact upon Patient and those around them. This includes practical steps such as researching the illness to facilitate Patient and Others' understanding of it, accessing support groups in order to reduce the pressure upon one's family, and organising a will and belongings to make these tasks more manageable for Others after Patient has died. A key and prominent area has been the focus upon Patient collecting and processing information related to their illness and treatment, tying in with the notion that '...information and awareness are two fundamental issues in any health care process' (Corli et al., 2009, p357). This possibly demonstrates a more recent shift in how patients are viewed by the medical profession and may be partly due to the availability and accessibility of this information via the internet.

In addition, there is an overarching feature of the guidance offered which relates to the relationship between the Patient's wishes and context of health, in particular making good use of the time available to Patient (Innes and Payne, 2009). These

processes can also be connected with mental processes of desideration relating to Patient wishes. This feature appears to correspond with or be a response to what was found to be the Patient's wish for '...enhanced control and planning, issues that acquire particular significance towards the end of life, when a finite time remains in which to fulfil goals, and at a time when control may be considerably diminished by the illness' (Innes and Payne, 2009, p32).

Additionally, there is significant focus upon emotional steps such as Patient managing their feelings in order to relieve some of the emotional strain upon themselves and their loved ones. This involves actions such as confronting fear and thoughts rather than avoiding them and would seem to tie in with the belief that the emotional aspects of terminal illness can be as much of a challenge as those of a physical nature. In some respects, the prominent focus upon emotional activity can also be linked to recent findings in palliative research that '... there is a close association between low mood and physical symptoms in patients with advanced cancer' (Lloyd-Williams et al., 2004, p562).

These guidelines also include material processes in areas which are expected to overlap with other process types. For example, processes in this group regarding how to communicate effectively so that Patient can use the right words to explain the illness and prognosis to their children. These examples are akin to those outlined previously within similar verbal processes and indicate that advice on specific aspects of living with cancer often includes similar advice being incorporated across a combination of related process types.

4.7 Patient as Goal in Advice Data

The next participant role to be discussed is that of Goal, accounting for over 5% of Patient's participation. This low frequency may be considered surprising owing to the expectation that Patient would have appeared in a role whereby they are acted upon with greater frequency. This may suggest that the patient is not seen primarily as being acted on, as one might expect according to traditional views of the medical domain.

In the case of these processes, the tendency for one type of material process to be more prominent is apparent, as with Patient in other participant roles such as Actor and Circumstance, but more pronounced where Patient is Goal. Here the majority of examples can be categorised as intention and account for close to 83%, which is almost 20% higher than for Patient as Circumstance. With processes of intention forming the majority of material processes in which Patient appears as Goal in the advice data, it may be worth considering the nature and range of examples in this category. The following groups of processes have emerged from this categorisation.

Table 62: Key processes for Material Processes of Intention with Patient as Goal in Advice Data

Types of Activity	No	%
Helped/cared for etc	35	57
Being treated physically/medically (before and after death)	17	28
Non-medical but undesirable actions related to illness & treatment	5	8
Being treated in general (how people treat/behave towards you)	3	5
Non-medical action	1	2
Total	**61**	**100**

By far the highest number relates to processes in which Patient is helped or cared for in some way. In itself, the nature of these processes may well be expected, but this does not detract from the fact that the overall frequency is lower than anticipated. The nature of this group of actions tends to be somewhat general rather than specifically medical. Although it could be argued that health related actions may well form part of being cared for, it seems that explicit expression of

medical care emerges in a separate category and the most common material processes for Patient as Goal are expressed in more general terms.

The second largest group has been categorised as 'being treated physically and medically' and relates to processes in which Patient is Goal both before and after death. This group differs from the previous in terms of more specific reference to treatment and physical actions 'done to' the Patient as opposed to being 'cared for' as Goal. A further point is that several of the examples in this category relate to processes directly within the medical gaze such as being diagnosed, treated or cured. In some cases, they relate to processes which are strongly associated with end stage terminal illness such as how the Patient's body is treated in the final stages and after death. In this respect it could be suggested that Patient as Goal here is represented more in the manner of 'object' than 'person', given the nature of the processes involved.

Table 63: Material Processes of Medical and Physical Treatment with Patient as Goal in Advice Data

Treated = 6 Diagnosed = 3 Moved = 2 Touched = 2 Moistened = 1 Cured = 1 Cremated = 1 Buried = 1	Being treated physically/medically (before and after death) = 17

Leading on from this, in addition to considering the types of material processes for Patient as Goal, it may also be useful to address the matter of who or what is acting upon Patient as Goal in these material processes. An overview of the main Actors can be found in figure 40 below.

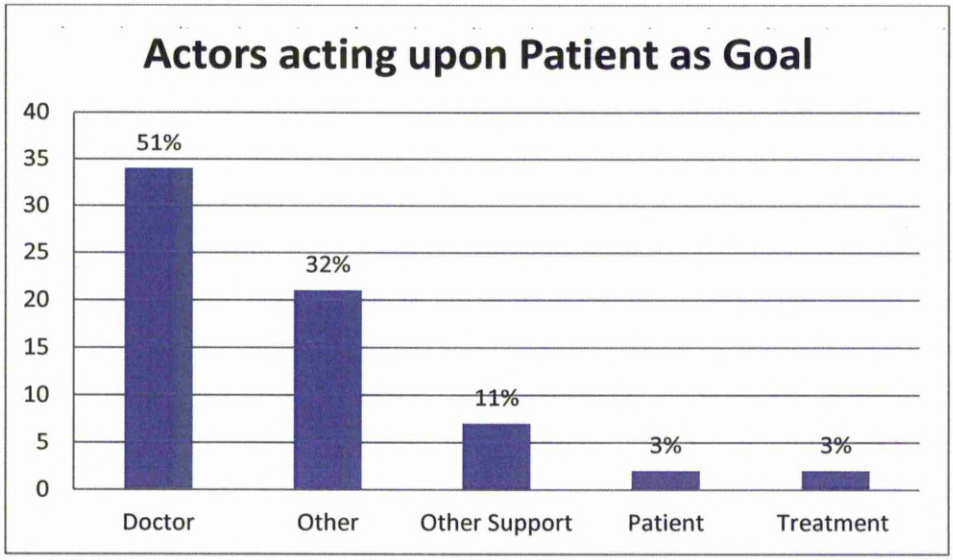


Fig. 40 Actors acting upon Patient as Goal in Advice Data

The most prominent Actor acting upon Patient as Goal, at 51%, is Doctor. Given the number of processes outlined previously which fall within the sphere of medical care and treatment, this outcome is perhaps not entirely surprising. However, it should be noted that a large number of these relate to very general processes of being Patient 'helped', 'cared for' and 'looked after' rather than specific medical procedures. The second most significant Actor acting upon Patient as Goal emerges as Other although Other's participation is not exclusive in these instances. There is a large degree of role sharing with other entities in that 90% of processes involving Other also involve role sharing with Doctor or Other Support. Similarly to processes involving Doctor, these often coincide with somewhat general processes of 'helping', 'caring for' or 'looking after'.

The next Actor accounts for just over 10% of instances and these involve the Other Support acting upon the Patient. These processes also tend towards role sharing with Doctor and Other and this occurs in almost half of the examples found. Therefore, over half of these examples bear some similarity to processes in which Doctor and/or Other act upon Patient and involve 'helping' Patient. However, there is one respect in which Other Support differs from all other Actors acting upon Patient and this may be due to the fact that this group of Actors includes people

such as undertakers and related professionals. As a result over 40% of processes in this sample relate to processes which take place after death such as burial, cremation or some form of appropriate treatment of the body after death.

At this point it may be possible to draw some tentative conclusions about the participation of Patient as Goal owing to certain tendencies in the data so far which could be worth noting and monitoring. First is the overriding nature of the material processes in which Patient is Goal as those of a 'helping' kind, further to which is the often more generalised, rather than specifically medicalised, help and support. A further point of note concerning process types for Patient as Goal may be the low incidence of processes which relate to activity beyond the scope of health, illness, caring and death. Given the medical context and purpose of the advice texts, this might have been expected. However, the implication is that action upon Patient as Goal takes place within the medical gaze and does not include any examples of non-medical activity. This represents Patient solely within a medical framework and excludes all other types of possible activity directed upon them.

Regarding key Actors and a possible transitivity template is the predominance of Doctor and Other as Actor. In addition to this, and quite possibly due to the generalised nature of the 'help' given to Patient as Goal, there seems to be a tendency towards role sharing in that there are several instances in which Doctor and Other take the role of Actor jointly, such as 'the people who are looking after you...'. This happens in 25% of the examples in which Patient is Goal. Also, but less so, there are instances where the role is jointly taken by Doctor and Other Support, as in 'your body is treated in the appropriate way after death', which relate to health care staff and professionals such as undertakers. These account for a further 5% of Patient as Goal in the advice data. On the basis of this sample, it may be that there is a greater affinity for Actor role-sharing within this data when Patient is Goal. However, this can only be verified by comparing this tendency with other participant roles and the data taken from patient interviews.

Finally, it is possible to calculate the dynamic value of Patient in the advice data by applying Thompson's system of weighting (2006) to the participant roles for Patient. The following table shows that Patient's participation as Actor, Sayer and Senser are primarily responsible for the level of dynamism in the advice data.

Table 64: Overall Participation of Patient in Participant Roles in Advice Data in Order of Dynamism

ROLE	Weighting	No	Score
Initiator	+3	2	+6
Attributor	+3	10	+30
Actor + animate goal	+2	17	+34
Actor + inanimate goal	+2	150	+300
Actor – goal/+ scope	+1	279	+279
Behaver	+1	36	+36
Sayer	+1	181	+181
Senser	+1	216	+216
Token	0	1	0
Value	0	0	0
Carrier	0	311	0
Beneficiary	-1	27	-27
Phenomenon	-1	8	-8
Scope	-1	2	-2
Goal	-2	76	-152
Receiver		26	
Verbiage		0	
Target		5	
Attribute		5	
Existent		0	
Circumstance		68	
Total		**1420**	**+891**

Chapter Five: Interview Data Results and Discussion

5.1 Patient Participation in Interview Texts

The following section will consider and summarise Patient's participation within the interview data, overview all participant roles and focus upon those of greatest frequency. The results are presented in order of dynamism and frequency in the tables below. Those in bold on the following table indicate a minimum level of 1%.

Table 65a: Overall Participation of Patient in Participant Roles in Interview Data in Order of Dynamism

ROLE	No	%
Initiator	4	0.5
Attributor	6	0.5
Actor + animate goal	**19**	**1**
Actor + inanimate Goal	**100**	**7**
Actor – goal or + scope	**198**	**14**
Behaver	**15**	**1**
Sayer	**105**	**8**
Senser	**337**	**25**
Token	8	0.5
Value	**15**	**1**
Carrier	**285**	**21**
Beneficiary	**33**	**2**
Phenomenon	**28**	**2**
Scope	1	0.1
Goal	**83**	**6**
Receiver	**27**	**2**
Verbiage	7	0.5
Target	2	0.2
Attribute	2	0.2
Existent	7	0.5
Circumstance	**97**	**7**
Total	**1379**	**100**

Table 65b: Overall Participation of Patient in Participant Roles in Interview Data in Order of Frequency

ROLE	No	%
Senser	337	25
Carrier	285	21
Actor – goal or + scope	198	14
Sayer	105	8
Actor + inanimate Goal	100	7
Circumstance	97	7
Goal	83	6
Beneficiary	33	2
Phenomenon	28	2
Receiver	27	2
Actor + animate goal	19	1
Value	15	1
Behaver	15	1
Token	8	0.5
Verbiage	7	0.5
Existent	7	0.5
Attributor	6	0.5
Initiator	4	0.5
Target	2	0.2
Attribute	2	0.2
Scope	1	0.1
Total	**1379**	**100**

As in the discussion of the advice data, the most frequent participant roles for Patient will be discussed in order to consider patterns which might emerge in the grammatical representations of Patient in the interview data. Following on from this it will be possible to highlight similarities and differences between the patient interview and advice data, where these emerge from the findings.

5.2 Patient as Senser

Evidently, the most frequent role for Patient in the interview data emerges as Senser in mental processes. Mental processes account for 24% of Patient's activity and this is a greater proportion than the most significant participant role within the advice data. This in itself demonstrates a change from the advice texts in that Senser was not the most frequent role for Patient within that data. An overview of Patient's participation as Senser can be found in the chart below.

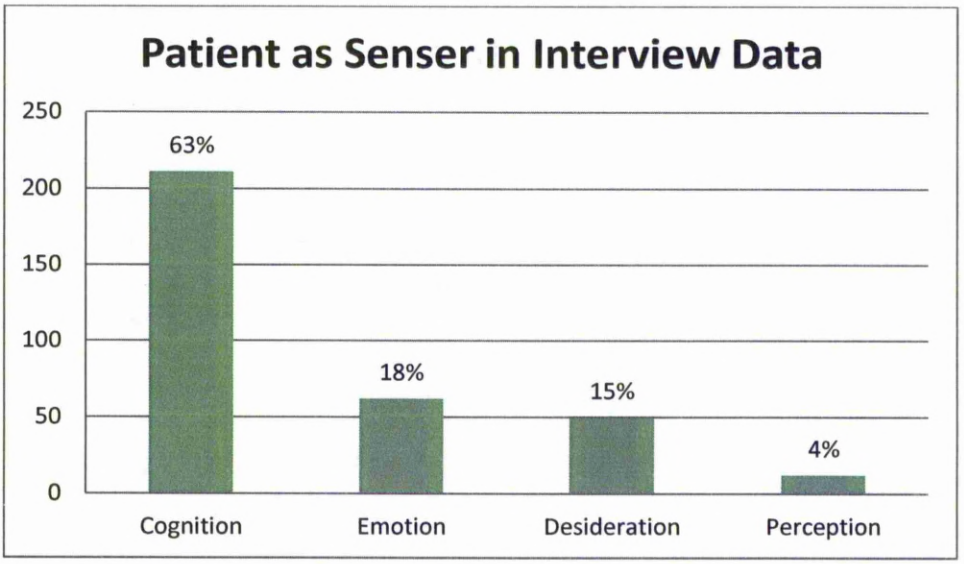


Fig.41 Patient as Senser in Interview Data

Within the interview data, the overall pattern of distribution of mental processes from greatest to smallest is broadly similar to the advice data although the extremes are more pronounced. Variations are that Patient appears as Senser in a larger proportion of mental processes of cognition and emotion and a lower proportion of processes of desideration and perception. Furthermore, in the mid range, Patient engaged in marginally more emotion based processes than desiderative. This may be of some significance because within the advice data, the reverse was true and the difference between the two process types was greater. In this section each will be summarised in order of frequency.

5.2.1 Processes of Cognition

The most significant type of mental activity for Patient in the interview data, comprising 63%, relates to cognitive processes in which Patient thinks, knows and believes certain things. As the table below indicates, these three key processes when combined make up almost 70% of Patient's cognitive activity. This represents Patient as a person with a noticeable measure of opinions, knowledge and beliefs.

Table 66: Overview of Patient's Processes of Cognition in Interview Data

Process of Cognition				**Number**	**%**
Think	72	Not think	13	85	40
Know	16	Not know	16	32	15
Believe	24	Not believe	4	28	14
Feel				14	7
Find (out)				14	7
Remember	4	Not remember	4	8	4
Realise	3	Not realise	2	5	2
Understand				5	2
Expect				4	2
Discover				3	1
Decide				3	1
Forget				1	0.5
Wonder				1	0.5
Ignore				1	0.5
Learn				1	0.5
Suppose				1	0.5
Imagine				1	0.5
Suspect				1	0.5
Take into account				1	0.5
Recognise				1	0.5
Guess				1	0.5
Contemplate				1	0.5
Mean				1	0.5
Total				**213**	**100**

The findings suggest that an increased focus upon Patient opinion as outlined in the literature (Armstrong, 1984; Chambers et al., 2003; Woods, 2005; Finlay, 2005) is reasonable and in keeping with the Department of Health guidelines and policy reviews (2003; 2008) in which Patient opinion is considered a central component in

the provision of medical care as shown by recent patient-centred directives such as INVOLVE, Patient Voices and the Expert Patient programme.

As with the advice data, examples which were felt to be modal expressions or discourse markers were not included as mental processes. Nevertheless, it may well be that the interview data contains expressions of opinion with greater frequency owing to the nature of the discourse in which patient's opinions are being sought. However, that this is the aim of the interview is, in itself, significant because it represents a new focal point in medical discourse in which the Patient's mental activity is considered and patients have opinions which appear to be valued. Examples of this can be found in 'I thought I'd got another forty years to live', 'I believe in the afterlife' and 'part of me realises that they're not going to be able to help me'. This is in contrast to more traditional approaches in which there was little attention to what patients might think or know and their beliefs were not considered relevant in the face of medical opinion.

This recent change suggests medical opinion itself has transformed in this respect and that patient opinion is now being acknowledged and responded to. This is particularly evident in the interview data which represents Patient as informed and knowing; the 'doctor-patient' (Sarangi, 2001; Vegni et al., 2005). In addition to this, the interview Patient is represented with a greater emphasis upon their beliefs and values, as in 'when you believe in God' and ı believe in the teaching of my church that it's not acceptable'. They have beliefs and values which in the context of terminal illness and end of life are not only to be acknowledged and respected, but potentially deferred to in order to facilitate a good death (Fletcher and Freeling, 1988; Gaskin, 1997; Ellershaw 2002; Jahad et al., 2003).

A further feature of this group is that a wide range of cognitive processes are evident and this is suggestive of a cognitively active Patient engaged in various mental processes of not knowing as well as knowing, of researching and learning about their illness and treatment. Within the interview data there is greater emphasis upon Patient opinions and knowledge, as in 'I just thought it was

indigestion' and 'I understand that the majority of women that are treated for breast cancer it's successful treatment'.

However, there is less emphasis upon research-related activities such as 'each person with an illness of this kind needs to see, find out who their key worker is'. It could be argued that this suggests that the Patients being interviewed are in possession of the knowledge which the advice data proposes they research. It is also worth noting that in the interview Patient is slightly more likely to 'not know' than to 'know', as in 'I don't know any electricians', and this is akin to the manner in which the advice data normalises Patient's lack of knowledge.

This profile of mental activity bears some similarities to that in the advice data with the addition of mental processes of a more challenging nature such as ignoring, suspecting and questioning. This layer of mental activity was absent from the advice data and introduces a less compliant dimension to Patient; the 'critical thinker' Patient.

In combination with the cognitive processes, it is also necessary to consider what it is that Patient thinks and knows about or believes in. Therefore, the key Phenomena overall have been summarised below.

Table 67: Overview of Phenomenon in Patient's Processes of Cognition in Interview Data

Phenomenon	No	%
Treatment	23	12
Afterlife	16	10
Euthanasia	11	7
Death/dying	11	7
Doctors /Nurses	10	6
Diagnosis	9	5
Life	9	5
End-of-life wishes/matters	9	5
Illness	8	5
Religion	7	4
God	6	4
Suffering/pain	5	3
Mobility	5	3
Help/support	5	3
Telling children	4	2.5
Health of carer	4	2.5
Communication skills	3	2
Hospice	2	1
Patients	2	1
Suicide	2	1
Honesty	2	1
Changes in Doctor-Patient Communication	2	1
Recovery	2	1
Our bodies	1	0.5
The universe	1	0.5
Stages of grief	1	0.5
Acceptance	1	0.5
Hospital	1	0.5
Reincarnation	1	0.5
Patient confidentiality	1	0.5
Physical exercise	1	0.5
Expensive things	1	0.5
Poetry	1	0.5
Love	1	0.5
Openness	1	0.5
Dairy products	1	0.5
Diet	1	0.5
Doctor's explanations	1	0.5
My wife	1	0.5
Total	**173**	**100**

As with Patient's cognitive processes, the overview above presents a wide range of Phenomena which are the focus of Patient's mental activity. It is of interest that treatment emerges as the most significant focus for Patient, in 12% of cognitive processes, as in 'but I knew there was a possibility they might want to give me other cycles'. This is of particular interest because it was not evident within Patient's cognitive processes in the advice data. In connection with this, the Interview Patient expresses views on the world of medicine and engages in evaluating it, as in 'I think the human side of medicine is lacking' and 'I felt they were probably taught how to give injections and do blood pressures'. Again this represents a new dimension to Patient as one with knowledge and opinions about their treatment who is aware of and prepared to assess aspects of medical training and provision.

There is also significantly more attention to Patient's views on matters of life and death, end of life and euthanasia, such as 'I had thought about suicide'. This represents Patient's views and philosophy on existential and ethical matters such as how they view their place in the world, their bodies, their approaching death. Examples of this are 'I feel that our bodies are like the bodies of animals', 'I'm content to believe that I'm all part of a much bigger thing', 'I think living wills and euthanasia are the same thing', 'I think morally and ethically it's wrong'. Patient views also extend to their view of the world when they are no longer in it, as in 'I couldn't imagine her (*my wife*) staying down here on her own'.

It is also possible to group together related Phenomena into Patient's domains of experience, as in the following table.

Table 68: Phenomena According to Patient's Domains of Experience in Processes of Cognition in Interview Data

Phenomena Grouped	No	%
Health, illness, medicine	78	45
Life and death	62	36
Religion and beliefs	13	7
Communication	10	6
People, personal qualities	10	6
Total	**173**	**100**

As shown above, the dominant domain is health, illness and medicine, which is consistent with findings in the advice data and not entirely surprising. This represents the interview Patient as knowing and thinking about their illness and treatment and more aware of and cognitively responsive to their context of health.

Life and death is the second most significant domain for Patient in the interview data. In this group, although 'life' emerges, it is more related to the existential aspects of life than the everyday life which emerges in the advice data. An example of this is 'I believe in the afterlife'. A further dimension of the interview Patient's cognitive activity is the focus upon religion which was found to be absent from the advice data. This therefore indicates that the Phenomenon which the Interview Patient actually engages with cognitively differs in some respects from that represented in the advice data; that Patient knows, thinks and believes differently from how we might expect based on the advice data.

5.2.2 Processes of Emotion

18% of the interview Patient's overall mental activity relates to processes of emotion and in contrast to the advice data, this is not only a larger proportion, but also greater than desiderative processes. The key processes can be found in the

table below in order of frequency, followed by combined processes according to semantic groups.

Table 69: Overview of Patient's Processes of Emotion in Interview Data

Process	No	%
Accept	9	14
Like/don't like	8	12
Come to terms with	5	8
Worry/don't worry	5	8
Enjoy	4	6
Bother	4	6
Trust	3	5
Love	3	5
Cope with	3	5
deal with	2	3
Fear/don't fear	2	3
Appreciate	2	3
Welcome	2	3
Take (accept)	2	3
Impressed	1	2
Grieve	1	2
Surprised	1	2
Relate to	1	2
Look forward to	1	2
Face	1	2
Tempted by	1	2
Satisfy	1	2
Total	**62**	**100**

The most common type of emotional process relates to accepting and these are all stated positively, as in 'I accepted it (the diagnosis)' and 'I accepted it (my illness)'. This presents the interview Patient as one who is accepting of rather than resistant to their illness and its terminal nature, which is not necessarily a predictable reaction. It may be that this is representative of the final key stage of grief for the interview Patient (Kübler-Ross, 1973) and an emotional coping strategy for coping

with loss (Forshaw, 2002). In contrast, it has also been found for acceptance to be a potentially misleading preface to 'false hope' in terminally ill patients (Hinton, 1999).

The next most common process type relates to 'liking', the majority of which are positive, as in 'I like gardening', with a few negative instances, as in 'I don't like strangers poking around my belongings'. Accepting and liking emerge as the most significant processes of emotion for the interview Patient, significantly more engaged in processes of positive emotion than negative. These have been grouped together and summarised in the table below.

Table 70: Overview of Patient's Processes of Emotion in Interview Data Grouped

Process Type	No	%
Positive emotion	28	45
Accepting	16	26
Negative emotion	12	19
Coping	6	10
Total	**62**	**100**

This presents a largely positive representation of Patient's processes of emotion when analysed and categorised solely at the process level. For example, 'don't worry' is counted as negative according to the process 'worry', although it could be counted as positive if it were analysed at the clause level. However, it is also important to bear in mind negativity grammatically as well as semantically. For example, 'worry' has been analysed as a negative process of emotion semantically and yet only appears in examples such as 'don't worry' or 'stop worrying'. The overall effect of this interplay between negativity grammatically and semantically is that the interview Patient is represented as participating in overwhelmingly positive processes of emotion and even advising against negative processes of emotion, as in 'I wouldn't worry about pain'. The picture which emerges is of a Patient who has accepted their illness and whose mental processes of emotion are largely positive, encompassing what Patient likes, enjoys, loves, trusts, copes with, appreciates and

welcomes. Patient is involved in reacting emotionally to their illness but mostly in a positive sense. Beyond the realms of illness, Patient reacts to Phenomenon beyond the context of health, such as 'I enjoy life' and 'I appreciate my family and friends'. Perhaps surprisingly, Patient even engages in positive processes regarding end of life arrangements, as in 'we were very impressed by the general memorial service'.

Examples of more negative processes of emotion include 'we can fear death' and 'you grieve, not for yourself but for other people, relatives'. However a more typical feature of negative processes is that they are often negated, as in 'that it (death) may be five years downstream doesn't bother me' and 'not to fear death'. These present the interview Patient as aware of the negative emotional processes but actively advocating the avoidance of them.

When compared with Patient in the advice data, there is a greater tendency towards positive processes. If considered on semantic grounds, the ratio of negative to positive is one in four and with grammatical negation, as outlined above, accounted for, this positive slant is slightly more pronounced. An interesting feature of the interview Patient's emotional processes is that in over 10% of instances, they engage in processes which can be described as almost 'anti-negative' processes of emotion such as, 'pain control needn't worry one', ' I would stop worrying about it' and 'I have stopped worrying'. Therefore, not only is the interview Patient more likely to engage in positive processes of emotion, there is also evidence of Patient actively managing their negative emotional processes in a way that reduces their negative impact upon Patient.

Following on from this it is also possible to overview the key Phenomena for Patient in processes of emotion. These are given in the table below.

Table 71: Overview of Phenomenon in Patient's Processes of Emotion in Interview Data

Phenomenon	No	%
Diagnosis	7	15
Prognosis	6	13
Death	6	12
Life	6	12
Illness	3	6
Euthanasia	3	6
Family and friends	3	6
Pain	2	4
Garden/gardening	2	4
Emotions	1	2
Belief	1	2
Memorial service	1	2
Help	1	2
God	1	2
Reality	1	2
Shocks	1	2
Artificial life support	1	2
Hospice day centre	1	2
Activities	1	2
Intrusion from others	1	2
Total	**49**	**100**

The detailed overview indicates a wide spread of Phenomena for Patient in this group which can be summarised further into domains of experience.

Table 72: Phenomenon According to Patient's Domains of Experience in Processes of Emotion in Interview Data

Domains	No	%
Illness	18	37
End of life, death	11	22.5
Life, activities	11	22.5
Emotions, belief, religion	4	8
People	3	6
Care	2	4
Total	**49**	**100**

The types of Phenomena and domains of experience in which Patient's processes of emotion emerge are remarkably similar to those found in cognitive processes. Illness is the most significant Phenomenon, as in 'I accepted it (my illness)' and 'you come to terms with the illness'. Interestingly, the overview of Phenomenon presents an equal balance between life and death, such as 'I enjoy life very much' and 'I would welcome euthanasia'. With the exception of 'communication' in cognitive processes and 'care' in emotion processes, all other domains appear in both process types. This suggests that there is not as clear a division of Phenomena according to process types as was found in the advice data.

It is also evident that whilst there is greater homogeneity of Phenomena across the interview Patient's types of mental processes, there is a degree of variation when comparing Phenomena in one type of process, in this case emotion, across the data sets.

5.2.3 Processes of Desideration

15% of Patient's overall mental activity relates to processes of desideration; that is activity related to wanting. This figure is significantly lower than for the advice data and indicates that the interview Patient places less emphasis on this aspect of their mental activity than the advice data suggests. The table below lists key processes in this category, which will be overviewed prior to considering typical Phenomena in this group.

Table 73: Overview of Patient's Processes of Desideration in Interview Data

Desideration	No	%
Want/don't want	29	58
Pray	10	20
Would like	7	12
Hope/hope not	2	4
Intend	1	2
Rather	1	2
Total	**50**	**100**

As with the advice data, the main process in this group is to want or not want. However, there is a greater emphasis upon the negative form, with Patient 'not wanting' in over half of these instances. For example, 'I don't want more chemo', 'I don't want to be resuscitated' and 'I don't want a life hereafter'. These can be regarded as significant in general because in Patient preferences and Doctor's expectations of those preferences may not necessarily coincide. For instance, discrepancies have been found between patients' anticipated and actual preferences for prognosis disclosure (Miyashita et al., 2006). Overall, the interview Patient is involved in not wanting the following Phenomenon, whilst the table after presents Phenomenon which Patient is involved in wanting.

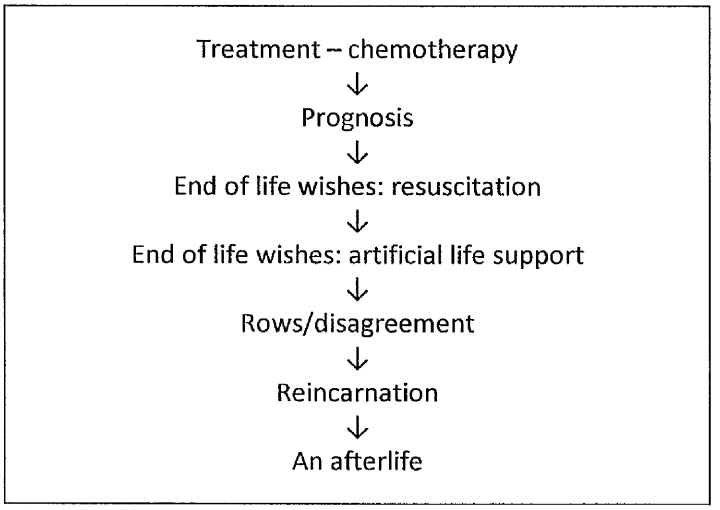


Fig. 41 Patient's Anti-wish List

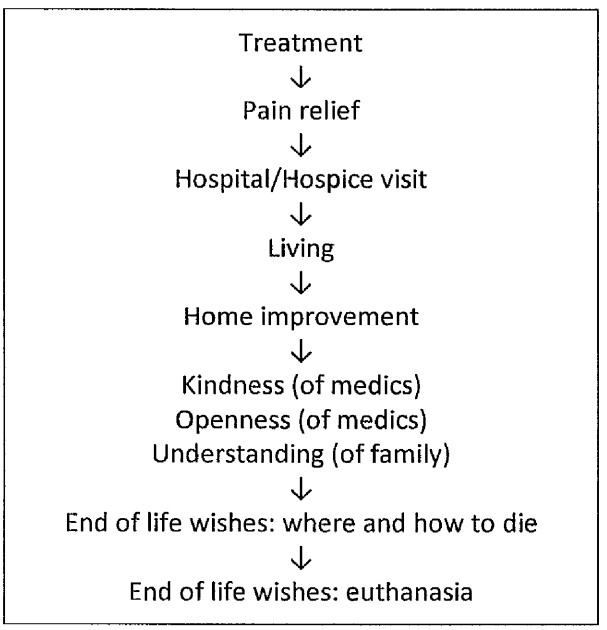


Fig. 42 Patient's Wish List

Further points to highlight include the use of 'pray' which, although overlapping with verbal processes, appears within mental processes of desideration when also used to express wishes such as 'I pray for a deepening of faith all the time'. Moreover, expressions of 'hope' appear in which Patient 'hopes' in relation to their end of life wishes and the fulfilment of them. Processes of hoping were entirely absent from the advice data and their presence in the interview suggests a slightly stronger resemblance between patients who have been the subject of research on Patient choices, preferences and hopes (Nekolaichuk et al., 1999; Nekolaichuk and Bruera, 2004) and the interview Patient, than the advice data Patient. Although few in number, the literature suggests that this is an area of significance within current medical research which merits attention (Eliott and Olver, 2002).

Following on from the key processes of desideration, it is also possible to overview the typical Phenomena involved in this group, as listed in the following table.

Table 74: Overview of Phenomenon in Patient's Processes of Desideration in Interview Data

Phenomenon	No	%
End-of-life wishes	10	22
Treatment	7	14
Afterlife	5	11
Faith/belief	4	10
Euthanasia	3	8
Rows/upset	2	5
Pain relief	2	5
Hospital/hospice visit	2	5
Living	1	2
Death	1	2
Home improvement	1	2
Grace	1	2
Openness	1	2
Kindness	1	2
Understanding	1	2
Lack of care	1	2
Prognosis	1	2
Going out	1	2
Total	**43**	**100**

Similarly to Phenomenon in other mental process types, these can be grouped into domains of experience for Patient thereby providing an overview of the main focal points for Patient's processes of wanting.

Table 75: Phenomena According to Patient's Domains of Experience in Processes of Cognition in Interview Data

Phenomena Grouped	No	%
End of life	20	46
Treatment, care	15	30
People, personal qualities	8	19
Living	2	5
Total	**45**	**100**

The main focus is clearly upon end of life matters and Patient's wishes and preferences in relation to this, such as 'I would like to have an easy death'. As with the advice data, this is the most frequent Phenomenon in such processes with increased frequency for the interview Patient. Treatment and care also emerge as significant Phenomena with an additional feature relating to the personal qualities of the people providing that care, such as 'what they want is kindness'. These examples present the stipulated wishes of Patient regarding desirable qualities and conduct of the professionals and carers in their lives. As such this introduces an additional aspect to the interview Patient who wants their care delivered in a particular manner and considers these personal qualities to be of importance to Patient. This represents a Patient who has specific service requirements and engages in evaluation of and feedback on that service (Jahad, et al., 2006). This more assertive Patient differs significantly from the silent and passive model patient of the past and can be labelled the 'customer-patient'.

The table below compares Phenomena in processes of desideration in both the interview and advice data. Several similarities emerge, in addition to the shift in focus from Patient wanting information about their illness in the advice data to wanting particular personal qualities in their carers according to the interview data.

Table 76: Comparison of Phenomenon According to Patient's Domains of Experience in Processes of Desideration in Interview and Advice Data

Phenomenon	Interviews		Advice	
	No	%	No	%
End of life	20	46	21	34
Treatment, care	13	30		
Care, support, treatment			12	19
People, personal qualities	8	19		
Living	2	5		
Living/activities			16	26
To discuss illness			9	15
Ask for/get info about illness			4	6
Total	**43**	**100**	**62**	**100**

5.2.4 Processes of Perception

Processes of perception comprise 4% of the interview Patient's overall mental activity and make up the smallest group of mental processes. Examples of this group are 'I see all the complications of it (euthanasia)' and 'you see so many people in the same boat'. The key processes and Phenomenon are listed below.

Table 77: Overview of Patient's Processes of Perception in Interview Data

Perception	No	%
Find	6	50
See	3	25
Hear	2	17
Feel	1	8
Total	**12**	**100**

Table 78: Overview of Phenomenon in Patient's Processes of Perception in Interview Data

Phenomenon	No	%
Illness/symptoms	4	34
Treatment	3	26
Medical equipment	1	8
Nurses' comments	1	8
Complications of euthanasia	1	8
Patients	1	8
TV programmes	1	8
Total	12	100

The most common process in this group is that of finding, noticing or registering the Phenomenon of symptoms and responses to treatment. Examples of this are 'The minute I found that third tumour' and 'I find I'm getting a bit constipated'. Based on previous research (Driscoll, 2000), these can be viewed as typical examples of Patient's processes of perception which take place within the medical gaze. They can also be regarded as typical because Patient is responsible for noticing and reporting symptoms even within more traditional medical models of the past. In addition to this, the interview Patient can also be seen as engaging in processes of perception which are not merely passive reporting of symptoms. For example, 'whenever I felt I needed it (analgesics, paracetamol, Tramadol) and 'if I find that they're not controlling the pain to my satisfaction' represent Patient as also actively involved in monitoring symptoms, responses to treatment and instrumental in modifying treatment. This could be taken as further evidence of the interview Patient as 'doctor-patient' (Sarangi, 2001; Shaw and Baker, 2004) whereby Patient is involved in processes which might be more typical of a doctor. However, it is not clear that the interview Patient is acting in lieu of the doctor but may be more a case of a 'co-doctor' patient whereby Patient's processes of perception are part of a collaboration with their medical team. These examples can also be categorised as

evidence of patients' coping strategies in which Patient engages in direct action regarding treatment strategies which are indicative of a problem-focused approach to coping with advanced cancer, as outlined by de Faye et al. (2006).

Finally, in order to compare the interview Patient with the advice Patient, an overview of the Phenomenon for processes of Perception from both data sets is given below. This indicates that the only Phenomena which is common to both sets is that of illness and treatment. This area has emerged as key in all types of mental processes and so the overview below offers conformity in this respect. However, as with processes of emotion, there is some variation of Phenomenon within the same type of mental process when comparisons are made between the two data sets.

To conclude the interview Patient's mental processes the following points can be highlighted. Firstly, the participant role of Senser emerges the most frequent for Patient in the interview data and this marks a change from the advice data. Secondly, cognition is the most frequent type of mental process and Patient is mostly involved in acts of thinking, knowing and believing, most often in relation to illness and treatment but also connected to domains such as end of life matters, death and spirituality.

Regarding other process types, the interview Patient is involved in processes of emotion more than desideration and both involve key Phenomena similar to the most frequent for cognition. Processes of Perception are the least common but involve similar key Phenomena. Overall, this suggests a certain level of homogeneity of Phenomenon across mental process types for the interview Patient. The key Phenomena for Patient as Senser in all types of mental processes in the interview data can be found below.

Table 79: A Comparison of Key Phenomenon in Mental Processes

Process / Type / Phenomenon	Cognition	Emotion	Desideration	Perception
Health, illness, medicine, treatment	45%	37%	30%	68%
Life and death, end of life	36%	22.5%	46%	8%
Religion and beliefs	7%	8%		
People, personal qualities	6%	6%	19%	8%
Communication	6%			
Life, activities		22.5%	5%	
Care		4%		8%
TV programmes				8%
Total	**100%**	**100%**	**100%**	**100%**

In comparison with the advice data, the interview Patient is represented as more involved in mental processes with a far higher incidence of cognitive processes. They are also more engaged in processes of emotion and less in processes of desideration, where the reverse is true for the advice Patient. One point of similarity is that the least common type of mental process for both Patients is that of perception. In terms of cognitive processes, the interview Patient is more likely to know and hold opinions on medical matters than the advice Patient who is engaged in discovering and learning about their illness and treatment. The interview Patient also emerges with traces of critical thinking which are not evident in the advice data.

Processes of emotion present a wider range and more positive emotional activity for the interview Patient than the advice Patient, suggesting that the interview Patient is slightly more emotionally engaged, active and willing to express emotions than the advice text writers have anticipated. Regarding processes of desideration, the interview Patient emerges as willing to stipulate what they do and do not want,

particularly in relation to end of life choices. Finally, processes of perception present both Patients noticing Phenomena such as symptoms although the interview Patient appears more actively engaged in monitoring responses to treatment and the required adjustments to treatment based upon these perceptions.

A final point to highlight is the interplay between different types of mental activity. For example, Schofield et al. (2003) have established a relationship between Patient's processes of desideration regarding the provision of information about treatment and their emotional reaction, particularly related to anxiety and depression. A second link was found between Patient's cognitive processes regarding treatment and increased levels of hope. Although it is not possible to identify interaction between types of mental processes in the current study, this aspect of Patient's mental activity should not go unmentioned, for in reality, it has been found to be of importance to medical researchers (Dougherty et al, 1986; Grumann and Spiegel, 2003; Schofield et al., 2003)

There is also the consideration that Patient's mental activity cannot be regarded as fixed and constant and that a typical feature of these processes is their tendency to change, sometimes dramatically, on a regular basis. This tendency has been found to be further exacerbated within and by the context of terminal illness (Dougherty et al., 1986; Chochinov et al., 1998; Chochinov et al., 1999; Viederman, 2000). Therefore, the overview presented here is based on what is hoped is a reasonably representative sample of different Patients' mental activity during the day(s) on which they were interviewed.

5.3 Patient as Carrier

The following section will outline Patient's participation as Carrier in the interview data in processes of being or having, with related attributes. Patient takes this role in over 19% of the interview data and it is the second most frequent role for Patient in this data set. This is slightly less than in the advice data where this role was the most frequent for Patient and accounted for a slightly larger proportion of the advice Patient's overall participation. In the same way that the analysis of the advice data was designed to reveal something of the writers' views of Patient, it is hoped that the interview data will reveal something of the Patients' view of themselves in terms of identity and qualities.

The relational attributes which are ascribed to the interview Patient can be divided into the three main types of intensive, possessive and circumstantial, as outlined earlier in the advice data. Examples of each are given below with the relevant statistics. The overall order of frequency is identical to that of the advice data. However, there are proportional differences in that the percentage of intensive attributes is lower than in the advice data, with possessive and circumstantial emerging as higher.

Table 80: Types of Attributes and Distribution across Interview Data

Type	Describing	Example	No	%
Intensive	qualities	I am open-minded	159	56
Possessive	ownership and belonging	you have a family	96	34
Circumstantial	location, time, quantity, matter	I was in a wheelchair	30	10
Total			**285**	**100**

The main type of attribute for Patient emerges as Intensive, accounting for 56% of attributive processes in the interview data. This group can be further subdivided according to types of intensive attributes ascribed, as shown below.

5.3.1 Intensive Attributes

Table 81: Types of Intensive Attributes and Distribution across Interview Data

Type	Example	No	% age
States with mental overtones	One can be afraid of a painful death	55	34
Health states	I hadn't felt ill	44	28
General States	I'm now eighty-five	41	26
Personal qualities	I'm always cheerful	12	12
Total		**159**	**100**

As mentioned previously, intensive attributes make up the largest class of attributes for the interview Patient. Within this class, the most frequent type of attribute emerges as states with mental overtones, followed by health states, general states and personal qualities. In terms of this overall pattern of distribution, there are some similarities with Patient in the advice data. The most and least common types are identical but there is an exchange of position between health states and general states in the two data sets. Each of the four key types of intensive attributes for the interview Patient will now be examined in more detail.

States with Mental Overtones

The most common kind of intensive attribute for the interview Patient is states with mental overtones, accounting for over one third of this group. As mentioned in the previous section, this type of intensive attribute could have been expressed within mental processes but appears in these examples as relational processes. For instance, 'One can be afraid of a painful death' could have been expressed as 'One fears a painful death'. States with mental overtones can also be categorised according to the type of mental process to which they are related, as shown in the table below with examples and statistics. Each will be overviewed in turn in the following sections.

Table 82: Patient's Intensive Attributes with Mental Overtones in Interview Data

Type	Example	No	%
Emotion	I felt sympathetic with her.	41	75
Cognition	I'm conscious of the fact that they are busy.	14	25
Total		**55**	**100**

Emotion based States

As the table indicates, 75% of Patient's states with mental overtones relate to emotion based states and the tendency towards this type of state with mental overtones is consistent with, but less pronounced than, the advice data. The states are outlined below in order of frequency and, where possible, in groups of attributes which are semantically related.

Table 83: Patient's Intensive Attributes with Mental Overtones - Emotion

Attribute	Number		%
Upset Bad Depressed In a state	1 1 2 1	5	12
Hesitant Nervous Uncomfortable Worried	1 1 1 1	4	10
Afraid	4		10
Happy	3		7
Surprised	3		7
Vulnerable	2		6
Let down	2		6
Sympathetic	2		6
Good	2		6
Angry Aggressive	1 1	2	6
Sorry	1		2
Trite	1		2
Bereaved	1		2
Grateful	1		2
Accepting	1		2
Motivated	1		2
Excited	1		2
At home	1		2
Confident	1		2
Content	1		2
Fulfilled	1		2
Brighter	1		2
Total	**41**		**100**

At a glance, this presents a broad range of mental attributes with a greater tendency towards negative than positive emotional states. Examples of negative states are 'I was also worried about the children thinking it would be hereditary' and 'when they say things like, "the cancer's spread", you get very, very upset'. More positive states can be found in examples such as 'I really am so grateful to them' and 'I'm very happy with those arrangements (not to be resuscitated). It is also possible to calculate the division of positive to negative emotional states which

is 54% negative, 39% positive and 7% neutral. This ratio is far less pronounced that the 90% negative emotional states found for Patient in the advice data and suggests that the interview Patient has a more positive focus than the advice Patient. Moreover, a finding of 39% of emotion-based states being positive is not to be overlooked as it presents a fourfold increase compared to the advice Patient and, given the context of health, an unexpected outcome. This will be explored further when considering attributes and triggers below.

From the table above it is possible to draw together certain groups of related attributes and consider the typical triggers for each group in order to gain a better insight into these states with mental overtones and how they relate to the interview Patient's experience. In some cases, no trigger is mentioned but those key triggers which emerge for attributive states with mental overtones of emotion are outlined below.

Attribute	Key triggers
Upset Bad	diagnosis, emotions

Attribute	Key triggers
Hesitant Nervous Uncomfortable Worried	euthanasia, the possibility of somebody wanting to get rid of their relatives, assisted suicide, about the children thinking it would be hereditary

Attribute	Key triggers
Afraid	a painful death, death

Attribute	Key triggers
Angry Aggressive	pain, about getting satisfactory pain control

Attribute	Key triggers
Sorry	for people you leave behind

Attribute	Key triggers
Surprised	at how much help there is, I got MRSA, at how very loving and kind they (nurses) were

Attribute	Key triggers
Accepting Content	diagnosis, to believe that I'm all part of a much bigger thing

Attribute	Key triggers
Grateful Sympathetic	doctors/nurses, other patients

Attribute	Key triggers
Confident	about the pain, deciding on home v hospice
Good	from reiki
Brighter	from reiki
Happy	with those arrangements (not to be resuscitated), for that (*home nursing*) to happen to me

Based on the attributes and triggers above, it is possible to identify some general patterns. Firstly, as with the advice data, a range of negative states of emotion are expressed, such as 'I did become quite depressed' but there is a higher incidence of positive states in the interview data, such as 'I'm sufficiently fulfilled to think that okay, I will die'. The increase in positive states of emotion via the interview Patient introduces an unexpected dimension to Patient, whereby the interview Patient deviates from the advice Patient and from research findings which have found less evidence of positive emotions and states of emotions amongst patients with advanced cancer (Grumann and Spiegel, 2003; Johnston, 2004c; de Faye et al., 2006; Tamura et al., 2006a, 2006b; Lloyd-Williams et al., 2007).

Perhaps predictably, one trigger for Patient's states is their illness, symptoms and treatment. In contrast to the advice Patient, not all states were found to be negative and, as noted earlier in relation to mental processes, a more confident and assertive Patient emerges from this data set. This can be seen in examples such as 'I

do feel quite confident about the pain' and 'I will be aggressive about it (getting satisfactory pain control)'. The latter example in particular may be regarded as further evidence of the 'client' patient who is demanding of a particular service, in this instance 'satisfactory pain control', and prepared to insist upon it in no uncertain terms, to the point of being aggressive. This move towards Patient with emotional states of aggression may be regarded as a particular form of patient non-compliance. Ordinarily, compliance or non-compliance in patients is taken to refer to health behaviour whereby the patient does not comply with medical advice and fails to adhere to the requirements of their doctor (Donovan and Blake, 1992; Foreshaw, 2002). In this instance, it represents a specific type of behaviour whereby the interview Patient does not comply with the accepted attributes of a typical patient and fails to adhere to the typical role requirements of a non-aggressive patient (Duxbury, 2000). This non-compliance to role can be viewed as either deviance (Jeffery, 1979) or rational non-compliance (Sarafino, 1994) based upon the interview Patient's belief that their pain relief is inadequate.

Furthermore, illness is not the most common trigger and several of the interview Patient's states of emotion appear to be prompted by death and euthanasia, as in 'assisted suicide in Sweden makes me very uncomfortable'. Surprisingly, not all states triggered by death are negative, as in 'I'm sufficiently fulfilled to think that okay, I will die' and this may offer evidence from the interview Patient of what is referred to as 'death salience'. This awareness has been correlated with 'mortal extreme experience', such as terminal illness, which can be defined as 'an inability to deny the reality of personal death by a person who has life' (Little and Sayers, 2004, p1332).

Both illness and end of life matters can be seen as falling within the medical gaze and are examples of Patient's responses to physical and existential issues (de Faye et al., 2006). This is also true of triggers such as 'I really am so grateful to them' and 'I was surprised at how very loving and kind they were', both of which refer to nurses as triggers for positive states. Thus, it can be argued that the majority of the interview Patient's attributive states with mental overtones of emotion appear

within the same domain of experience; that is terminal illness and medicine. Exceptions to this can be found in 'one can be sorry for people you leave behind' and 'I was also worried about the children', in which the trigger is Patient's family, although it could be argued that these triggers are not entirely disconnected from the domains of terminal illness and death. They do, however, serve to represent Patient in relationships with people other than nurses, as a person with a family which leads to certain states with mental overtones of emotion and are examples of Patient's responses to social issues and relationships (de Faye et al., 2006).

Cognition based States

The remaining 25% of Patient's states with mental overtones relate to cognition-based states. These mental attributes are related to cognitive ability, knowledge, awareness and beliefs and the key states are overviewed below.

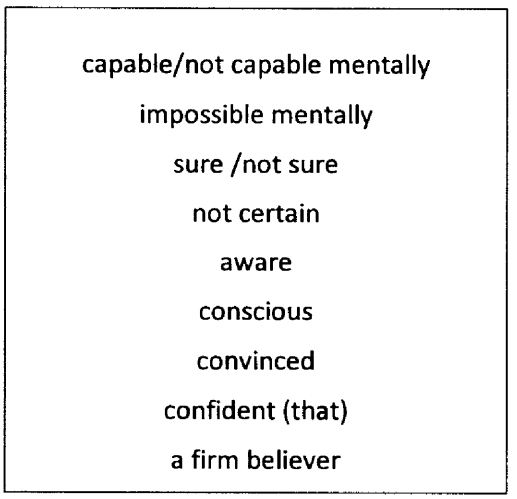


Fig. 43 Patient's Typical cognition based states

In general, the interview Patient appears to be capable, knowledgeable, certain, convinced, confident and aware. There are instances where Patient is not sure and not capable but these are few and the result is that the interview Patient is represented with mostly cognitive states which are positive in emphasis. Where

evident, the domains of experience in which these appear are listed below and can be said to fall exclusively within the medical gaze of terminal illness.

Fig. 44 Domains of Experience for Patient's cognition based states

However, the interview Patient is also aware of the possibility of a loss of cognitive function, as in 'if I'm not capable, they will (make the decisions)' and 'unless I become, oh impossible one way or another, mentally or physically'. The following figure summarises Patient's states with overtones of cognition, ranging from knowledge, opinions and capacity.

Attribute	**Context**
Sure	that they'll give me enough morphine
Aware	as fully aware as I am of every aspect of my illness
Confident	that I can deal with that (deciding on home v hospice)
Not sure	that I want to be told that it's a year away
Convinced	that there is life after death
A firm believer	that some of you, part of you will continue in other people after you're gone
Capable	of making decisions
Not capable	of making decisions
Impossible	mentally

Fig. 45 Patient's typical cognition based states: knowledge, belief and capacity/ incapacity

Finally, an overall comparison can be drawn between states with mental overtones and their corresponding mental process for the interview Patient, as overviewed below.

Table 84: Comparison of States with Mental Overtones and Mental Processes

States with Mental overtones	%	Mental processes	%
Emotion	75	Emotion	18
Cognition	25	Cognition	63
Desideration	0	Desideration	14
Perception	0	Perception	4
Total	**100**		**100**

To summarise the key similarities and differences between states with mental overtones and mental processes, it is clear that states with overtones of emotion are proportionally more prevalent than mental processes of emotion. Regarding cognition, this is far less evident within states with overtones than within mental processes. Similarly to the advice data, this presents a reversal of emotion and cognition depending upon whether it is encoded as state or process. A further point to note is the absence of states with overtones of desideration and perception which also bears some similarity to the Patient in the advice data.

Health States

Following on from states with mental overtones, a number of other attributes are ascribed to the interview Patient. The next most frequent of these relates to health states, which accounts for 28% of Patient's intensive attributes, only marginally less than the proportion found in the advice data. Examples of this group are 'I feel very weak physically' and 'I became ill' and relate to states of physical health and fitness. The table below shows health states as they appear in order of frequency.

Table 85: Interview Patient's Health States

Health States	No	%
Ill, sick, poorly	16	37
Better	5	11
Worse	3	7
Tired, weak	3	7
Good	2	5
Ready to die	2	5
Terminal	2	5
Well	2	5
Dependent	1	2
Bedridden	1	2
Impossible physically	1	2
Dead	1	2
Gone	1	2
Alive	1	2
Mobile	1	2
Fit	1	2
Energetic	1	2
Total	**44**	**100**

The most common health state refers to being ill, sick or poorly, describing a state of ill health. This describes a more general health state with the addition of more specific health states such as 'I'm feeling a bit sort of tired' and 'I feel very weak physically' following on from this. This larger group can also be divided into groups of positive and negative health states, comprising 29% and 71% respectively. The largest of these, the negative health states as shown below, will be considered first.

Table 86: Interview Patient's Negative Health States

Health States	No	%
Ill, sick, poorly	16	37
Worse	3	7
Tired, weak	3	7
Terminal	2	5
Ready to die	2	5
Dependent	1	2
Bedridden	1	2
Impossible physically	1	2
Dead	1	2
Gone	1	2
Total	**31**	**71**

Quite predictably, the interview Patient's health states are considerably more negative than positive. These range from the general state of being ill or sick to more specific states such as 'she was terminal', and 'they were bedridden'. Overall these negative health states can be seen to represent a transition from general states of illness to the specific and ultimate negative health state of death, as outlined below. The fact that the particular progression route of health states below bears a strong similarity to that ascribed to Patient in the advice data suggests that the interview Patient is aware of the states likely to be experienced as they navigate this route. This awareness and the precision of its likeness to the corresponding route set out by the advice data may also be indicative of Patient's acceptance of dying (Hinton, 1999).

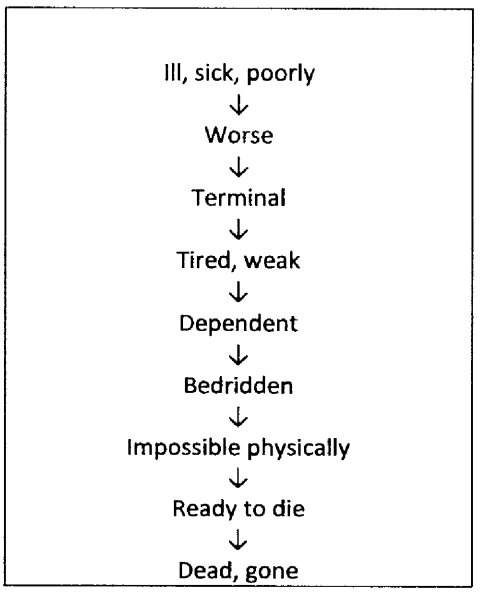


Fig. 46 The Path of Negative Health States

In addition to negative health states, positive health states can be found in examples such as 'I'm feeling much more energetic' and 'you're going to get better'. In contrast to the negative health states, these states range from the simple state of being alive to states of recovery and wellness. As the table below shows, the most common positive health state for the interview Patient relates to being and feeling 'better', accompanied by several other general and positive health states

such as 'good' and 'well'. More specific positive health states for the interview Patient relate to mobility, energy and fitness.

Table 87: Interview Patient's Positive Health States

Health States	No	%
Better	5	11
Good	2	5
Well	2	5
Alive	1	2
Mobile	1	2
Fit	1	2
Energetic	1	2
Total	**13**	**29**

These mirror the negative health states in the presentation of general to specific health states. They can also be overviewed in terms of a broader transition from a basic state of being 'alive' to a more active state of feeling 'energetic', as summarised below.

Fig. 47 The Path of Positive Health States

General States

The next group of intensive attributes for Patient relate to general states, as opposed to those of health or with mental overtones. This group accounts for 26% of Patient's intensive attributes and include examples such as 'I may be wrong about euthanasia' and 'each patient is an individual'. Similarly to health states, these examples can be divided into positive and negative states, with the addition of states such as 'by the time I was 60' which cannot be ascribed to either and are thus classed as neutral. These are summarised below.

Table 88: Positive, Neutral and Negative States in Intensive Relational Processes

Type of State	Example	No	%
Positive	I've been lucky	19	46
Neutral	if you're a driver	13	32
Negative	I may be wrong about euthanasia	9	22
Total		**41**	**100**

In general, the order of frequency is the same in the interview and advice data although the proportions vary in that there is a noticeably higher proportion of positive states and slightly lower percentages of neutral and negative states in this set. This conforms to the pattern established with mental processes of emotion whereby the emphasis upon positive states of emotion was found to be greater in the interview data than the advice data. This suggests a further grammatical context within which the interview Patient represents themselves and their experience in more positive terms than that suggested by the writers of the advice texts.

The positive states account for almost half of this group and examples which emerge from the interview data relate to attributes such as being entitled, ready, a person, an individual, friends, careful, lucky and simplistic. Examples can be found such as 'You're entitled to apply for some money' and 'we (are) just friends'. These

occur within a range of situations and contexts such as illness, care and treatment, along with non-medical contexts such as financial help, dealing with children, relationships, and self-image.

Almost a third of general states can be classed as neutral and relate to being physical beings, a certain age, in touch with medical professionals and in a particular role such as driver, gardener, carer or patient. Examples include 'our bodies are like the bodies of animals', 'I was in my late fifties' and 'If you're a bit of a gardener'. This group appears to stand further beyond the medical gaze in that although there is some connection at times, as in the first example above, several examples do not directly relate to the context of health. This suggests that in the current data set, neutral states may be more likely to emerge in a less overtly medical context. What does appear to emerge, however, is a Patient with multiple roles such as 'We're just custodians while we're here', 'I will go on to be a part of something else' and 'If you're a bit of a joiner', all of which represent Patient beyond the parameters of their patient role.

Negative states account for over 20% of general states and relate to attributes such as being wrong, alone, old, unable to go to the toilet, unable to bring in income, wood or stone, short of money and lazy. Examples include 'Apart from cancer I'm getting old' and 'you could tend to just half the time just be lazy'. Unlike the previous subgroup of neutral states, these are considerably more likely to relate to or be triggered by the context of health, as in 'I may be wrong about euthanasia'. This suggests that the interview Patient is more inclined to ascribe negative states to themselves within the context of health and the medical gaze.

The figure below provides an overview of the main contexts within which positive, neutral and negative states have emerged from the interview Patient. If compared with the advice data, a similar pattern can be found in both overall proportions of medical and non-medical contexts, as well as the distribution of positive, neutral and negative states according to medical and non-medical contexts.

Positive	Neutral	Negative
illness	self-image	health service
care	age	age
treatment	contact with medical academic	loss of mobility
financial help	our place in the universe	loss of earning power
dealing with children	non-patient ↔patient role	dealings with medical profession
personal relationships		financial problems
self-image		side effects

Fig. 48 Contexts of Positive, Neutral and Negative States

Personal Qualities

The smallest group of intensive attributes are those of personal qualities, which comprise 12% of the interview Patient's intensive attributes. In the same way that within the advice data this group may reveal certain personal qualities of Patient as ascribed by the writers of those texts, it is hoped that something will be revealed regarding the personal qualities which the interview Patient self-assigns. These can be divided further according to whether they are positive, negative or neutral qualities and an overview can be found below with examples.

Table 89: Positive, Neutral and Negative Personal Qualities in Intensive Relational Processes

Type of State	Example	No	%
Positive	I am open-minded	13	68
Neutral	some people are quiet	3	16
Negative	patients are very vulnerable	3	16
Total		**19**	**100**

As the table shows, the majority of the Patient's personal qualities are positive, with equal amounts of neutral and negative qualities. From this, it appears that the interview Patient represents him or herself in a positive light and gives greater coverage to their positive qualities. Examples of this are 'I'm honest', 'I'm always

cheerful' and 'we've been ultra-careful with him'. Examples of neutral qualities which emerge are 'different' and 'quiet', whilst negative examples are 'vulnerable', 'sensitive' and 'extravagant'. Overall, however, the interview Patient self-assigns largely positive personal qualities and this is in keeping with the pattern established in the advice data but to a greater extent. Therefore, this increased emphasis upon positive personal qualities, along with emotion based states and general states, provides further evidence of the interview Patients tendency towards a more positive representation than that of the advice data.

Before moving on to possessive attributes, it may be worth drawing some general comparisons with this overall outline of intensive attributes and that found in the advice data. In some respects, the pattern of intensive attributes ascribed to Patient is similar in both data sets. The main similarity is that states with mental overtones are the most significant group in both the interview and advice data. Health states are more frequent for the interview Patient than general states, whilst the reverse is true for the advice Patient. However, the difference between these two types is no larger than 2% in either data set and so a general similarity appears to be the close proximity of these two types of attributes in both data sets. Perhaps the main point of difference between the two data sets is in the greater frequency of personal qualities for the interview Patient, with an increase of 7% compared to the advice data. This suggests that this is possibly an area of greater significance for the interview Patient or one which they are more inclined to discuss and ascribe attributes than the writers of the advice data. Equally, it may be that this provides evidence of patient 'self-definition' (Armstrong, 1994) and as such, the higher incidence within the interview data is to be expected.

5.3.2 Possessive Attributes

Whilst intensive attributes account for 56% of Patients attributes in the interview data, a further 34% are possessive attributes, related to processes of 'having' as opposed to 'being'. The most frequent type of possessive attribute relates to the

'help and support' which Patient has, followed by 'beliefs, feelings and qualities'. The next most common groups of attributes are 'illness' and 'medicine' related, comprising 14% and 13% of the interview Patient's overall possessive attributes respectively. The table below provides an overview of the key groups of possessive attributes for Patient.

Table 90: Associated Attributes in Possessive Relational Processes

Possessive	No	%
Help, support	22	25
Beliefs, feelings, qualities	16	18
Illness	13	14
Medicine	12	13
Friends, family	10	11
Time	9	10
Life, death, end of life	8	9
Total	**90**	**100**

The first point to note is that there is a reversal of prominence regarding 'illness' and 'help and support' in this data set compared to the advice texts. The interview Patient possesses help and support more than any other attribute type, as in 'I've had help from social services' and 'I did need quite a lot of help and support'. This attribute group ranges from the more general type of help, as in the previous two examples, to the more specific, as in 'You have the Mobility Allowances', 'we actually have the hot lunches now' and 'I've got two nice ladies who come and do the garden'. The frequency and range of types of help and support which emerge from the interview data represent Patient, in terms of possessive attributes, as primarily supported on a number of levels ranging from finance, food, mobility and gardening. This covers a broad spectrum of assistance in which Patient has encompassing social, financial, domestic and personal support. It may also be of interest that the interview Patient represents this with greater frequency and therefore prominence than medical support and gives emphasis to social support as a health tool (Forshaw, 2002).

The second most common group of attributes relates to Patient's beliefs, feelings and qualities, accounting for 18% of possessive attributes. Although in this group there may be some overlap with mental processes, states with mental overtones and personal qualities, these examples have been encoded as possessive attributes, such as 'to have fear', rather than 'to fear' or 'be afraid'. Examples from this group include 'you've got to have a belief, a faith in yourself', 'we have a great fear of death' and 'they must have patience'. In contrast to the previous set of possessive attributes relating to external help and support, this group consists mostly of Patient's internal attributes of beliefs, feelings and qualities and contribute to the representation of a patient in possession of certain attributes as stipulated by the interview Patient. In this respect Patient's 'self-definition' (Armstrong, 1994) also incorporates and emphasises aspects of their internal locus of control as set out by Rotter (1966).

Attributes relating to illness and symptoms account for 14% of Patient's possessive attributes, which is considerably less than in the advice data. Examples of this include 'I acquired this illness', 'You've got a tumour' and 'she'd had oestrogen led breast cancer'. With the inclusion of illness and symptoms as possessive attributes, the interview Patient's self-definition moves towards a more predictable and traditional representation and shows the interview Patient as meeting certain requirements or 'role expectations' (Williams, 2004).

Following on from this, and with similar frequency, Patient possesses attributes related to treatment such as 'I'd had one or two MacMillan nurses', 'I had a lovely district nurse', 'I could have permanent nursing care' and 'You're going to need a fourth cycle'. In addition to more general medical and treatment attributes, there are two more specific dimensions to this subgroup which emerge from the interview data. Firstly, Patient stipulates specific interpersonal aspects of medical care, as in 'we need a lot of affection' and 'we need tender loving care almost as much as we need the drugs', with these examples indicative of Patient's need for intimacy as part of their care plan (Gilley, 2000). Secondly, Patient's medical and

treatment possessive attributes include examples such as 'I had a pump' and are of interest because they represent Patient with the potential to self-administer pain relief and provide their own treatment. This could be seen to offer further evidence of a new breed of 'doctor-patient' who operates with greater autonomy within terminal illness (Jeffrey, 1995) and the importance of autonomy as an ethical consideration within palliative care (Berger et al., 2007).

Three further subgroups of possessive attributes emerge for the interview Patient. These are family and friends, time and death. Examples of the first are 'you have a family', 'I have four grown up children and nine grandchildren' and 'I have a lot of friends'. These account for 11% of possessive attributes and represent Patient beyond the world of medicine, as part of a family and social network, which predates their illness. This also presents family and friends which are considered an important component of Patient's quality of life (Finlay, 2005). Examples of time are 'you've got many years ahead' and 'You've got another ten, fifteen years'. These comprise 10% and are often embedded within the reporting of mental processes. When considered in this context, they offer representations of the interview Patient's former self, with greater life expectancy prior to terminal illness.

The final subgroup of possessive attributes relate to life, death and end-of-life matters, with examples such as 'we have an afterlife', 'I would like to have an easy death' and 'both my wife and I had up to date wills in place'. These make up 9% of this group and are concerned with Patient's end of life preparation and preferences in terms of attributes which they have or would like to have and their presence can be seen as evidence of the interview Patient's acceptance of dying (Hinton, 1999).

To sum up Patient's possessive attributes, to some extent the interview Patient meets certain 'role expectations' in terms of having an illness and symptoms (Williams, 2004). However, this dimension is less evident in this data set and does not dominate as in the advice data. The findings suggest that the interview Patient has other attributes on a larger scale relating to help, feelings and family. This offers

a representation of Patient with attributes other than illness which, if frequency is taken as an indicator or significance, suggest that illness is not the most significant attribute for the interview Patient. In this sense Patient self-definition is at variance with patient definition as suggested by the advice data in that illness is not necessarily the main attribute by which patients define themselves. The interview Patient presents a wide range of possessive attributes; in addition to cancer, symptoms and treatment, they have families, gardeners, beliefs, feelings, a life and possibly an afterlife. In several interviews these attributes are given greater prominence than their illness. Furthermore, there appears to be some discrepancy between attributes ascribed to themselves by Patient and those they perceive as being ascribed by others. Examples of both can be found below and demonstrate a disparity between Patient's attributes and their perceived attributes. The first group shows attributes which are ascribed to Patient by Patient, whereas the second group of attributes are what Patient presents as attributes ascribed to them by medical people. In effect, this reveals something about Patient's assumptions of Doctor's assumptions about Patients.

I have a lot of friends
I had about sixty cards from various people
every moment of the life I've got

you have no points of view
you don't seem to have any feelings,
you've just got cancer

5.3.3 Circumstantial Attributes

The final 10% of Patient's attributes are circumstantial and are summarised in the table below.

Table 91: Patient's Circumstantial Attributes

Circumstantial	No	%
Doctor, hospice, hospital	7	23
Illness, symptoms	5	17
Similar situation	5	17
Geographical location	4	14
On earth	4	14
Home	1	3
With other terminal patients	1	3
Treatment	1	3
Children	1	3
A wheelchair	1	3
	30	**100**

A large proportion of these are related to illness and treatment, as in 'the last ward I was in', 'I was in pain' and 'when I'm in the terminal stages'. They also relate to geographical locations such as 'If one lives in some remote part' and 'we're in a university town with a medical school' or being with people, as in 'I love being with the children'. This subgroup can be reordered to show whether attributes relate to medical or non-medical contexts, as in the table below which shows that Patient is twice as likely to appear with circumstantial attributes which are medically related.

Table 92: Patient's Medical and Non-medical Circumstantial Attributes

Medical	**No**	**%**
Doctor, hospice, hospital	7	23
Illness, symptoms	5	17
Similar situation	5	17
With other terminal patients	1	3
Treatment	1	3
A wheelchair	1	3
Non-medical		
Geographical location	4	14
On earth	4	14
Home	1	3
Children	1	3
Total	**30**	**100**

Finally, the following table provides a general overview of different types of attributes and attributive processes for Patient in the interview data. This shows attributive areas which are common amongst process types and the number of instances of each. Medical attributes emerge as the largest single category although the three remaining types could also be combined to create a wider non-medical class of attributes.

Table 93: Patient's Attributes According to Process Type in Interview Data

Process Type / Attribute Type	**Intensive**	**Possessive**	**Circumstantial**	**Total**
Medical	44	33	20	97
General	41	31	9	81
Mental	55	16		71
Personal	12	12	1	25

5.4 Patient as Actor – Goal/+Scope

The third most frequent role for interview Patient is as Actor without a Goal or with Scope, accounting for over 14% of Patient's participation within the interview data. These are processes in which Patient is the Actor but their action does not impact upon a Goal. Processes can be categorised depending upon the nature of the activity and an overview of these can be found below. In terms of whether these processes are intentional or involuntary, the proportions are 87% and 13% respectively. Over half of involuntary processes relate to death as in 'I would rather just die cleanly'. The other key areas in which Patient is Actor in an involuntary process relate to their illness, birth and life.

Table 94: Interview Patient as Actor – Goal/+ Scope: Domains of Experience in Involuntary Processes

Involuntary	No	%
Death	16	53
Birth, life	8	27
Illness, symptoms	6	20
Total	**30**	**100**

Key groups of processes which can be identified within the full set of processes for Patient as Actor –Goal/+ Scope are given below in order of frequency. These have then been grouped into semantically related domains of experience in the table which follows, showing key areas of activity in this group related to treatment and care, activities and death.

Table 95: Interview Patient as Actor – Goal/+ Scope

Domains	No	%
Treatment, care	64	33
Death	36	18
Daily activities	27	14
Activities	18	9
Communication	12	6
Illness, symptoms	9	5
Jobs	7	4
Life	6	3
Future	4	2
Help	3	1
Birth	2	1
Afterlife	2	1
Information	2	1
Work	2	1
Earning	2	1
Total	**196**	**100**

Table 96: Key Domains of Experience for Interview Patient as Actor – Goal/+ Scope

Domains	No	No	%	%
Treatment, care	64		33	
Help	3	**67**	1	**34**
Daily activities	27		14	
Activities	18		9	**27**
Jobs	7	**52**	4	
Death		**36**		**18**
Communication	12		6	
Research	2	**14**	1	**7**
Life	6		3	
Future	4	**10**	2	**5**
Illness, symptoms		**9**		**5**
Birth	2		1	
Afterlife	2	**4**	1	**2**
Work	2		1	**2**
Earning	2	**4**	1	
Total		**196**		**100**

As the tables show, the most frequent domain of experience relates to treatment, care and support, comprising 34% of this group. These relate to processes of

specific medical treatment such as 'I'm going to the hospital' and 'I had my chemo'. This group also includes more general care and support such as 'going to the Marie Curie centre' and alternative therapies such as 'We have reflexology'. It may also be noteworthy that this domain of experience appears with significantly greater frequency in the interview data than in the advice data where it accounted for only 7% of the same group of processes. The increased focus within this data set suggests that the interview Patient may be more involved in this domain of experience and places greater emphasis upon treatment, care and support related processes than the advice data suggests. There is also evidence of a range of treatment and care related processes in which the interview Patient engages which extend beyond the parameters of traditional treatment processes. This is outlined below with examples ranging from traditional treatment processes to those in which Patient acts without medical supervision and self administers treatment. This outline differs from the more traditional treatment trajectory outlined in the advice data, as shown below. The latter points on the trajectory offer evidence of both the philosophy and practice within palliative care of acknowledgment and support for patient autonomy (Varelius, 2006; Woods, 2005).

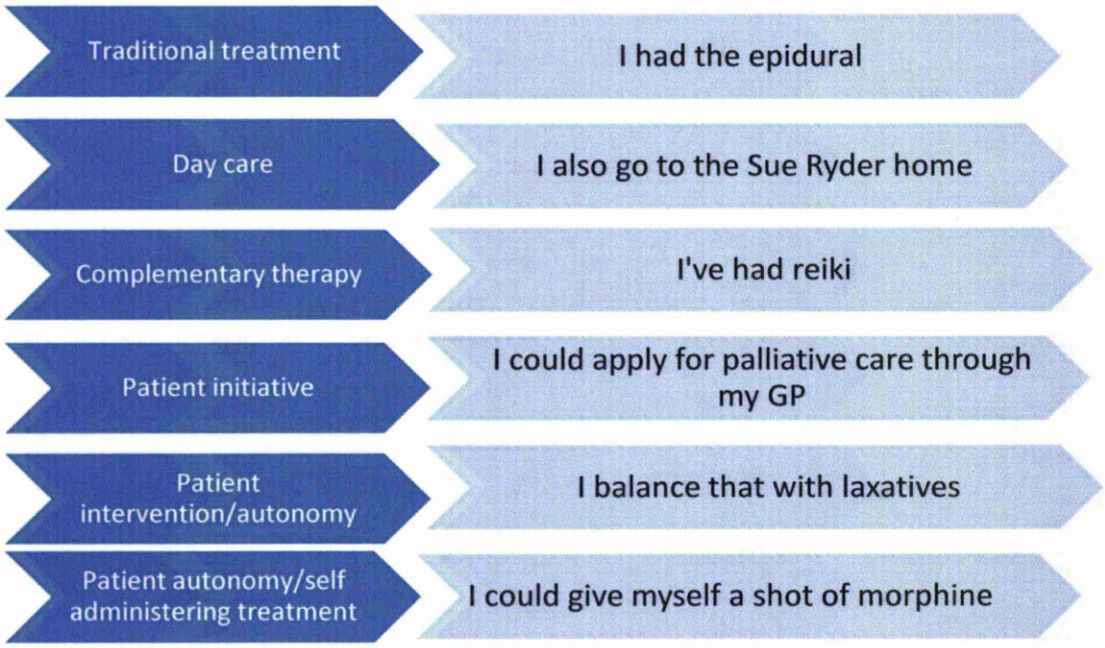


Fig. 49 Interview Patient as Actor –Goal/+Scope: the treatment trajectory

this group also includes other types of death and dying such as 'how I would go about it (suicide)' and 'I don't think people should do that (euthanasia)'.

In addition, although there is also 44% focus on dying related processes for the interview Patient, they differ from those present in the advice data. For example, the interview Patient's death related processes refer more to Patient's preparations for death with a significant focus upon administrative tasks, such as 'I never get to the end (of putting my papers into tidy order) and 'Any preparations one can make'. In contrast to this, dying related processes within the advice data tend to focus upon the accompanying physiological processes and loss of bodily function. The contrast demonstrates that whilst the advice data is concerned with preparing Patient for death and what they can expect of the process of dying, the interview Patient is more concerned with administrative and preparatory activities to be carried out prior to death, whilst able, to ensure that end-of-life wishes will be followed. Both represent pre-death activity but with varying focus on either pre-death processes of a physiological or practical nature. The former positions Patient firmly within the medical gaze with a focus upon the medicalisation of death (Connelly, 1997-1998), whereas the latter places Patient within a wider social context, making funeral arrangements, visiting solicitors, making arrangements for those people Patient will leave behind and considering the future beyond death (Lindqvist et al., 2008). The combined effect of the interview Patient's direct and related processes of death is the representation of a Patient whose awareness of and active involvement in their own death becomes integrated into their life, with Patient thereby engaged in confronting the issue of death (Yalom, 1980). Patient can be seen using a combination of problem-focused approach (de Faye et al., 2006) and task-based approach (Corr, 1991-1992) and this activity can be also viewed as indicative of the types of goals set by terminally ill patients in 'controlling dying, valuing life in the present, and creating a living legacy' (Nissim et al., 2012, p360).

The next largest subgroup of material processes for the interview Patient involves communication and research, accounting for 7% of instances in which Patient is

The next key domain relates to activities including everyday activities, leisure activities and specific jobs. Collectively, these make up 27% of the group and include daily activities such as 'I've started to do the cooking' and leisure activities such as 'the two of us had been going to the gym regularly'. Certain processes also relate to activities which Patient takes part in at their day care centre such as 'We do crafts and what have you' and Patient's 'to do' list, as in 'I'm doing all the jobs that needed doing'. Overall this represents an active patient, engaged in multiple activities. However, there are also instances which demonstrate Patient modifying the amount and type of activity they carry out due to reduced ability, strength or mobility. Examples of this include 'I can't run about with children', 'I can do a bit of gardening at a time', 'I can hardly walk' and 'I couldn't stand up'.

The following subgroup relates to Patient as Actor in processes related to death and dying, which comprise 18% of the set. This is slightly lower than in the advice data but similar in that it includes processes of dying such as 'you are going to die' and those which are related to dying, as in 'we might perhaps attend a general memorial service'.

Table 97: Interview Patient as Actor – Goal/+ Scope in 'Dying' Processes

Process	No	%
Dying	20	56
Dying related	16	44
Total	**36**	**100**

In comparison to the advice data there is a reversal of actual dying and dying related processes in that more emphasis is given to dying itself than death related processes by the interview Patient. This indicates that the interview Patient represents themself in this domain with greater frequency than the advice data and so may provide further evidence of the interview Patient possessing a higher degree of 'death salience' (Little and Sayers, 2004). The majority of cases relate to Patient's end-of-life wishes and a 'good death', as in 'you just slip away', although

Actor –Goal/ +Scope. The former can be found in examples such as 'I write', 'I write about the tree' and 'we started this interview' and tend to relate to general rather than medical information. However, examples do appear which are related to medical contacts such as 'CancerBACUP which is a telephone number that you can ring'. Moreover, there is a reversal of the proportions of processes related to communication and research compared to the advice data whereby communication takes priority over research activities for the interview Patient.

The next largest subgroups and domains for Patient as Actor account for proportions of 5% or less and so will be summarised briefly. The domain of life, living and the future appears with noticeably lower frequency than death, comprising 5% compared to 36% related to death and dying. Examples include 'We all want to go on living as long as possible' and 'Now we humans can look ahead'. This low frequency potentially represents Patient as not concerned with the life and the future as much as death and dying. However, it is also possible that the interview Patient's concept and definition of life and the future have been revised within the context of health and that notions of 'the future' have partially converged with approaching death. According to Lindqvist et al. (2008) changes have been observed in patients with advanced terminal illness in terms of their approach to time, over time. In particular, they place increased emphasis upon the period immediately leading up to death and the future also becomes related to the future beyond death. Evidence of these tendencies can be explored further when examining verbal processes in the following section.

Processes in the domain of illness in which Patient is Actor are also evident, to the same extent as those of time and the future. Examples of these include 'I got the MRSA' and 'people shouldn't have to suffer that much pain'. This group includes somatic symptoms such as 'I get a stabbing pain' as well as treatment-related symptoms, comprising two of the three key categories of symptom clusters as identified by Skerman et al. (2012). The third category, relating to lethargy and fatigue, has been identified in relational processes describing health states and so overall this offers a comprehensive sample of illness and symptom related

processes. However, the frequency with which illness and symptom related processes appear is lower than anticipated according to more traditional views of patient experience. A similarly low focus can be found in the advice data and this represents Patient in both data sets as more involved in other types of material processes than simply experiencing illness and having treatment. It may be of note that the literature suggests that the assessment of illness and symptoms is a significant area in medical research employing a range of tools (Chen, 2006; Skerman et al., 2009; Skerman et al., 2012), with particular emphasis on pain expression (Waddie, 1996). Patient, however, gives comparatively little coverage to this domain of experience in material and relational processes. A possible explanation of this may be found in the concepts of 'public pain' and 'private pain' (Wittgenstein, 1967) whereby the former is regarded as 'part of a public, communal language' (Waddie, 1996, p868), whilst the latter is the individual's private experience of pain, as opposed to the expression of pain through language. In short, according to the public-private dichotomy, the absence of processes involving pain and symptoms does not necessarily mean that the interview Patient is symptom and pain free. On the contrary, current research within nursing suggests that 'the silence of clients must not be taken to assume there is no suffering' (Waddie, 1996, p871).

The two final domains for Patient as Actor –Goal/+Scope relate to the world of employment and birth and the afterlife. The first of these can be found in 'the person who's ill is working'. These differ from certain employment related processes mentioned previously in that they represent Patient as actively working and earning despite their cancer, as opposed to no longer being able to.

The second minor set relate to birth and the afterlife. These may appear an unlikely combination but are presented by Patient as end points of their life and as key components of their view of themselves in the world. Examples include 'we came into this earth' and 'some of you, part of you will continue in other people after you're gone'.

To summarise Patient as Actor –Goal/+Scope, the key domains in the interview data have emerged as treatment and care, activities and death. Other domains which emerge in this group include communication and research, life and the future, illness and symptoms. Minor domains emerge as birth and the afterlife and employment. Overall, this presents a range of domains in which it may be of note that treatment and care appears to be a more significant area of experience than illness and symptoms. This could perhaps be anticipated and shows a reversal of the advice data in which the domain of treatment is less common than illness. In addition, the range of treatment and care processes introduce two aspects to the interview Patient which are not evident within the advice data. The first of these is Patient's participation in a range of therapies which are not restricted to typically medical treatments but involve activities such as reiki and reflexology. The significance of this can be seen in the definition of complementary medicine according to the Panel on Definition and Description, CAM as 'a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period' (1997, p50). This places the interview Patient within a domain of treatment and care which not only goes beyond the traditional biomedical model, but can also be seen as a challenge to it. This broader definition of care is also evident in palliative day care activities which although not always strictly medical, are considered to be components of the palliative care model. Examples of this form of care can be found in 'We start off with the atmosphere which is the music and relaxation (reiki)', 'you want to go to the hospice day centre', 'I don't miss one day (at the hospice day centre)' and 'Well it (Marie Curie centre) gives you things to do'. These examples highlight the role of palliative day care in supporting patients and as a key component in the philosophy of palliative care (Fisher et al, 2008).

A final consideration is how processes in which Patient is Actor –Goal/+Scope compare with other material processes in which Patient is Actor. The table below shows the three main types of material activity depending upon whether Patient acts upon a Goal and, where applicable, the type of Goal. The overall pattern found

here is remarkably similar to that found in the advice data and further examination of the domains of experience in processes with Goals will reveal similarities and differences within the interview Patient's participation as Actor in more detail.

Table 98: Interview Patient as Actor Interviews

Patient as Actor	No	% age
Actor - goal / + scope	196	62
Actor + inanimate goal	102	32
Actor + animate goal	19	6
Total	**317**	**100**

5.5 Interview Patient as Sayer

Patient takes the role of Sayer in over 7% of their overall participation and the following section will consider both Receivers and the types of messages which are passed on.

5.5.1 Patient as Sayer: Receivers

The vast majority of the 105 verbal processes in this group involve a Receiver or addressee, with only 12 instances where there is no obvious Receiver or addressee. As outlined previously, there are two types of recipients, the first being an explicit Receiver and the second type being an understood addressee who is not explicitly mentioned but whose role as recipient is clear from the context. Examples of each type can be found in 'how can I tell the children?' and 'If I was in pain I would ask for morphine'. In the first example the Receiver is clearly stated, whilst in the second it can be inferred from the context that the understood addressee is the doctor or nurse. The key Receivers to Patient as Sayer are overviewed in the table below. In some cases there is more than one type of receiver per verbal process.

Table 99: Receivers to Patient as Sayer in Interview Data

Entity	Explicit Receiver	Understood Addressee	Total No	%
Professionals	20	33	**53**	**54**
Other	15	10	**25**	**25**
Patient	4	7	**11**	**11**
God		10	**10**	**10**
Total	**39**	**60**	**99**	**100**

In processes in which Patient is Sayer the key Receivers are health or other professionals, Others, Patient and God. Over half of Patient's verbal messages are directed at health or other professionals, followed by over a quarter directed at

Others. Finally, Patient's messages are directed towards other Patients and God equally. In comparison with the advice data there is a reversal of the position and proportion of professionals and Others. A second point of contrast is the introduction of God as understood addressee in the interview data. A further difference is that there is a greater tendency towards understood addressees than explicit Receivers in verbal processes within the interview data, whereas the reverse is true of the advice data. This could be partly due to the purpose of the advice texts in recommending to Patient who to speak to or ask about certain issues whereas the interview data involves Patient reporting and planning verbal processes where explicit mention of the Receiver may not always be necessary.

The most frequent group of Receivers are professionals. This group is made up of medical professionals, with Doctors and nurses combined and Other support such as home help or social workers. Examples include 'whoever you're talking to, whether it's a GP, a consultant or nurse' and 'a person like me could ask for that service'. The figures for types of professionals as Receivers can be found below, showing that the percentage for medical professionals is significantly higher than other professionals. A similar pattern can be found within the advice data but is less pronounced than in the current data set, suggesting that in terms of verbal processes, the interview Patient engages more with medical professionals than might be predicted based upon the advice data.

Table 100: Overview of Professionals as Receivers to Patient as Sayer in Interview Data

Professionals as Receiver		%
Doctor = 43	52	83
Other support = 9		17

The second largest category of Receivers is Other which includes friends and family and the subcategory of children. Examples can be found in 'apart from saying to my sister-in-law "I went to the hospital today"' and 'I haven't told them how bad it is'. The numbers for each group of significant Others are given below and are lower than in the advice data, although overall percentages are not markedly different. One point to perhaps note is the absence of a third type of Other which was found in the interview data relating to employers and colleagues. This presents a narrower range of Others for the interview Patient, with verbal messages directed to friends, family and children, rather than Others outside the Patient's family and social circle.

Table 101: Overview of Other as Receivers to Patient as Sayer in Interview Data

Other as Receiver		%
Other (children) = 13		52
Other (friends and family) = 12	**25**	48
		100

The next type of Receiver to Patient's Sayer is Patient. In some cases this is the interviewee Patient talking to other Patients, as in 'you don't have time to discuss your illness' but may also be another Patient talking to the interview Patient, as in 'she said that she had got better'. Similarly to the advice data, there are instances of Patient as Sayer and Receiver in which Patients take both roles and engage in processes of mutual verbal support and understanding, with a sense of shared experience in terms of their terminal illness. This type of shared expertise is particular to Patient-Patient verbal processes and represents Patient in a role beyond their traditional scope, extending to a more supportive role, as in 'everything that she was saying it made... it spoke to me'. On the other hand, these Patient-Patient exchanges are not restricted to the context of health and examples

can also be found of Patients communicating on aspects of their experience beyond the context of terminal illness, such as 'We really don't have time to communicate over illness'.

The final type of Receiver to Patient's Sayer is God. This category is not evident within verbal processes in the advice data and thus introduces a new listener for the interview Patient. God is Receiver in 10% of the interview Patient's verbal processes and can be found in examples such as 'I pray for a deepening of faith all the time' and 'I pray for the grace to believe'. In all cases God is not explicitly mentioned but from the context and the process 'to pray', it can be assumed that the intended addressee of these messages and requests is God.

5.5.2 Key Receivers and Message Topics

In order to examine Patient's verbal activity more closely, it is also necessary to consider the types of messages being communicated. Therefore, in this section topics of verbal processes will be outlined and considered in relation to specific Receivers. The largest category of Receivers has been found to be professionals and so these will be considered first. An overview of the main topics for professional as Receiver can be found in the tables below. The first table lists topics in order of frequency, whilst the second contains topics which have been combined and regrouped according to related semantic fields.

Professionals as Receiver

Table 102: Overview of Topics for Patient as Sayer and Professionals as Receiver in Interview Data

Topics	No	%
Treatment	15	28
Illness	10	18
Symptoms	5	9
Help, support	5	9
Prognosis	4	7
Health state	3	5
End-of-life wishes	2	4
Afterlife	2	4
Acceptance	1	2
Belief	1	2
Patient status	1	2
Nurses	1	2
Doctor-patient relationship	1	2
Death	1	2
Emotions	1	2
Place in the world	1	2
Total	**54**	**100**

Table 103: Overview of Topic Groups for Patient as Sayer and Professionals as Receiver in Interview Data

Topic Clusters	No	%	
Treatment	15	28	
Illness	10	18	
Symptoms	5	9	71
Prognosis	4	7	
Health state	3	5	
End-of-life wishes	2	4	
Help, support, care	5	9	
Death	1	2	6
Afterlife	2	4	
Acceptance	1	2	
Belief	1	2	6
Emotions	1	2	
Nurses	1	2	
Doctor-patient relationship	1	2	
Patient status	1	2	
Place in the world	1	2	
Total	**54**	**100**	

Clearly, the most significant topic area to emerge from the interview Patient's verbal processes which are directed towards professionals relates to medical areas such as treatment, illness, symptoms, side effects, health states, prognosis and end-of-life. These all fall firmly within the medical gaze with the result that 71% of Patient's messages to professionals are concerned with medical matters. Such a finding may have been predicted, given the nature of the relationship between Patient and professionals within the context of health and the fact that the reporting of symptoms is considered to be a key component of traditional Patient – Doctor interaction. However, it may be of note that the most frequent topic, by 10%, is treatment, representing a relatively recent dimension of Patient as one who is involved in the discussion about their treatment (Janis, 1984; Armstrong, 1994; Jansen et al, 2001). Examples of this can be found in 'I said I'd like to go in again and have it drained off', 'I'm not asking anybody to overdose me or anything', and 'I didn't even have to discuss giving up chemo with the oncologist'. Such examples challenge the traditional information exchange between patient and doctor, introducing a role for Patient which extends beyond responding to the doctor's requests for symptom information, to include patient preferences and lay theories (Locker, 1983; Armstrong, 1994; Singer et al, 1999).

The next topic area within this medical group relates to the illness. Although, again this is a predictable topic area, it may be of interest to note that Patient is not involved in the more typical verbal process of reporting symptoms but instead engages in asking for information about their illness, as in 'ask any questions about your form of cancer'. This is perhaps indicative of the interview Patient's preferences for information in relation to their illness (Beisecker and Beisecker, 1990; Kaplowitz et al, 2002)

Within this group of topics which fall within the medical gaze, the following three appear but with lower frequency than treatment and illness and will, therefore, be summarised briefly. Firstly, 14% of Patient's messages to professionals are concerned with symptoms, side effects and health states such as 'I said to her ...I couldn't stand up' and 'If I was in pain I would ask (the doctor) for it (morphine)'. In

addition to these, there are also examples which reveal the interview Patient's displeasure when engaging in certain verbal processes such as 'having to explain, well I'm afraid I can't go to the toilet' and 'And I said, "Well look, I can hardly walk, I will wet myself by the time I get there"'. These examples are possibly indicative of an aspect of Patient-Doctor communication which, although related to symptoms and health states, does not comply with the traditional model of simple reporting of symptoms. These examples involve an element of discomfort for the Patient and the mere fact that they are voicing this within the interview may be an expression of the dissatisfied 'client-patient' whose satisfaction or lack of can be taken as an indication of their attitudes towards quality of care.

The next topic for Patient as Sayer to professional as Receiver relates to prognosis. As with the previous topics, this falls within the medical gaze and accounts for 7% of Patient's messages to professionals. Within the context of terminal illness, prognosis could be predicted as a topic of verbal processes. However, the more obvious pattern of exchange would be with Doctor as Sayer to Patient as Receiver, rather than the reverse as in the current data. In most cases, these messages relate to Patient asking or not asking for information relating to their prognosis, with a greater tendency towards not asking, as in 'I just haven't asked him (how many years)' and ''Well I haven't asked them specifically how many years'. Whilst these examples indicate a degree of knowledge of the general terminal nature of the prognosis, they also involve a lack of specific detail regarding the precise prognosis. This may be regarded as partial acceptance of the fact of prognosis without full information about the specific timescale involved. So although this does not represent Patient's denial of the prognosis, there is an element of avoidance in terms of them not asking for a specific prognostic timescale.

Such examples can be related to two aspects of medical and Patient-Doctor communication. The first of these is the general avoidance of prognosis which is found in Patient's verbal processes. This can be connected to the wider practice within medical training and medicine in which prognosis and prognosis disclosure are often overlooked. Textbooks give considerably more coverage to symptoms,

diagnosis and treatment, at the expense of prognosis. In fact, Christakis goes as far as to claim that there is a tendency within medicine 'to avoid the explicit discussion of prognosis and instead focus upon diagnosis and therapy' (1997, p301). This is partly reflected in Patient's verbal processes in that prognosis is less frequent than diagnosis and treatment and there is an extent to which Patient talks about it in the interview in terms of their information preferences but may not always want to know the prognosis in full and absolute terms.

Secondly, the examples found in the data represent the Patient as asker; requesting or not requesting prognostic information. This configuration places Patient in a position of leading the dialogue relating to prognosis and represents the interview Patient in a verbal role which might usually be ascribed to the Doctor. Overall, this suggests that the disclosure of prognosis may have become a more Patient-led discourse, which is supported by research which emphasises the importance of balancing availability and clarity of prognostic information with patient preferences regarding how much information the patient desires (Fallowfield et al, 2002; Innes and Payne, 2009).

The final topic within the medical gaze relates to end-of-life wishes such as 'We've told our GP about not wanting to be resuscitated'. Although there are very few instances of this in the interview data, their presence is significant in providing evidence of Patient communicating their end-of-life preferences and the importance of this in the role of achieving a good death (Steinhauser et al., 2000; 2001; Ellershaw, 2002; 2003; Ellershaw and Wilkinson, 2003).

The next most frequent group of topics bears some connection with the previous set of medically related topics. However, these relate to more general help and support of a non-medical nature and their inclusion within 9% of Patient's verbal processes demonstrates that the care and support required by the interview Patient is not confined to medical needs. Examples can be found in 'me to say thank you to all those that really have helped me' and 'a person like me could ask for that service'. Within this group, there is one instance of Patient thanking professionals

for help, whilst the remaining examples all relate to requests for help and support such as home help services.

Two further topics have been grouped together relating to death and the afterlife. These account for 6% of Patient's verbal messages to professionals, in this instance the interviewer, and include examples such as 'I will die and as I said earlier' and 'I don't want to go into this reincarnation etc too much'. A further 6% of messages are related to a group including belief, emotions and acceptance, as in 'people's belief in life after death as we've already discussed', 'When we mention emotions' and 'I can't really describe how I come to terms with it'. These examples also relate to mental processes but appear within Patient's verbal processes also as topics which they choose to discuss within the interview, thereby addressing some of the emotional and cognitive aspects of their experience of terminal illness such as emotions and death acceptance (Klug and Sinha, 1987; Redelmeier et al., 1993).

Of the remaining topics for Patient as Sayer to professional as Receiver, it may be worth noting that they offer both evaluations of medical professionals and commentary on the Doctor-Patient relationship. Examples are 'But the district nurses I'll praise' and 'well we touched on this earlier before, (open communication between doctor and patient)' and both can be taken as representations of a Patient who is quite removed from the traditional passive patient as of the past, emerging as the client-patient offering feedback and evaluation on the medical professionals they encounter.

Before considering the next set of Receivers, a general comparison can be made between the topics for Patient as Sayer to professional as Receiver in both the interview and advice data. This overview indicates that the interview Patient is likely to talk about matters relating to death and post-death as well as matters relating to the doctor-patient relationship and roles whereas the advice Patient's topics do not relate to these areas but instead focus upon matters relating to work, the law and daily life. The core areas which are relevant for both Patients fall within the medical gaze and emotions.

Table 104: Comparison of Topic Groups for Patient as Sayer and Professionals as Receiver in Interview and Advice Data

Interview	Advice
Treatment Illness Symptoms Prognosis Health state End-of-life wishes	Illness Treatment End-of-life choices
Help, support, care	Help, care
Death Afterlife	
Acceptance Belief Emotions	Feelings
Nurses	
Doctor-patient relationship	
Patient status	
Place in the world	
	Daily life
	Laws
	Work

Other as Receiver

The following group of Receivers to Patient's Sayer are Others, comprising 25% of Patient's verbal processes within the interview data. This group of Receivers is made up of family, friends and children. Initially, topics for the group as a whole will be considered and due to the fact that children as receivers were given specific attention in the advice data, this subgroup will also be examined in further detail. The key topics for Patient as Sayer to all Others are presented in the table below.

Table 105: Overview of Topics for Patient as Sayer and Other as Receiver in Interview Data

Topics	No	%
Illness	9	32
Treatment	8	28
Diagnosis	8	28
Prognosis	1	4
Dying	1	4
Thanks for help	1	4
Total	**28**	**100**

As with professional as Receiver, illness and treatment emerge as the most significant topics for verbal messages to friends, family and children. However, the order of frequency is reversed in this group where illness appears with greater frequency than treatment. The next most common topic to Others relates to Patient's diagnosis and combined with illness and treatment, means than 88% of Patient's messages to Others are firmly within the medical gaze. If prognosis and dying are also included, 96% of these messages are medically related. The remaining 4% relate to thanking Others for their help and care. Examples of each key type are given below, followed by a comparison of message topics directed to Others in the interview and advice data.

Table 106: Overview of Key Topics for Patient as Sayer and Other as Receiver in Interview Data

Topics	Example
Illness	so I made it quite clear that this is not a hereditary illness
Treatment	I discussed it (giving up chemo) with my wife and my eldest daughter
Diagnosis	I didn't say that ...mummy's going to be, you know, terminally ill

Table 107: Comparison of Topic Groups for Patient as Sayer and Other as Receiver in Interview and Advice Data

Interview	Advice
Illness	Illness
Treatment	Treatment
Diagnosis	
Prognosis	
Dying	
Thanks for help	Care
	Feelings
	Communication
	End-of-life choices
	Social invitation

As the table above shows, there are only three common themes within both data sets and these relate to illness, treatment and care. Rather surprisingly, the comparison of topics represents the interview Patient's verbal messages to Others as largely framed within the medical gaze whereas the advice data contains topics such as feelings and social invitations which take Patient beyond the realms of illness and treatment.

Further comparisons can be drawn when considering Patient as Sayer to children as Receiver. In the interview data these account for 13% of the interview Patient's Receivers, as opposed to 37% in the advice data. The key topics for messages from Patient to children are given below with examples from the data.

Table 108: Overview of Topics for Patient as Sayer and Children as Receiver in Interview Data

Topics	Example	No	%
Diagnosis	"I have to tell you, I've got cancer"	8	50
Illness	so I made it quite clear that this is not a hereditary illness'	6	38
Treatment	' did tell them I was back at the hospital	2	12
Total		**16**	**100**

The topics above can be found with other types of Receivers and one observation is that the range of topics for children as Receiver is narrower than for other Receiver groups so far. This reduced topic focus is also evident when comparing topics for children as Receiver in the interview and advice data, as outlined in the table below.

Table 109: Comparison of Topic Groups for Patient as Sayer and Other as Receiver in Interview and Advice Data

Interview	Advice
Diagnosis	
Illness	Illness
Treatment	Treatment
	Communication
	Child's emotions
	Patient's emotions
	Instructions to act

Evidently, the interview Patient passes on far fewer verbal messages to their children relating to fewer topic areas. Topics which do appear in the interview data relate directly and exclusively to the context of terminal illness. This is in contrast to the advice data which includes topics beyond this field. Furthermore, there is less evidence of the interview Patient following the detailed guidelines and procedures relating to diagnosis disclosure to children as outlined in the advice. Some isolated examples can be identified which might map on to certain stages in the process of breaking bad news to children such as 'So I said, "Well can you break it gently to the rest of the family?"'. However, examples within the interview data are few and do not provide a clear one-to-one relationship with all stages stipulated and strictly adhered to in the advice data. Therefore, whilst there is some evidence of the interview Patient following certain guidelines at times, there is also evidence of Patient disclosing their diagnosis to their children according to their own communication preferences. Examples of this are evident in Patient answering any questions the children might ask, as in "I'd tell them what they wanted to know'

but not necessarily divulging the gravity of the situation, as in 'I didn't say that the cancer's like gone all the way through my body and you know, and mummy's going to be, you know, terminally ill'. This approach represents Patient as exercising judgement and disclosing information at their own discretion rather than necessarily following each step of a fixed set of guidelines. This is suggestive of greater independence of thought on the part of the interview Patient who may not be deliberately deviating from professional advice but is likely to have greater expertise in terms of communicating with their own children on their terms, rather than according to rather general guidelines on how to communicate with children. . For example, the advice Patient is advised to avoid the use of euphemism and yet the interview Patient deliberately avoids the use of blunt and direct statements, as in the example above, followed emphatically by 'I didn't say anything like that'.

Patient as Receiver

Following on from Others as Receiver, the next most common group is that of other Patients. These account for 11% of Patient's Receivers and, as with other Receiver groups, predominantly relate to illness, as in 'much easier (for you) to talk to people who know about the illness' or 'We really don't have time to communicate over illness'. The remaining topics which Patients discuss, day care and alternative therapies, also have connections with the context of terminal illness. An overview of the topics identified for this group can be found in the table below and show that the topics discussed by Patients in the interview data are very closely tied to the context of health.

Table 110: Overview of Topics for Patient as Sayer and Patient as Receiver in Interview Data

Topics	No	%
Illness	5	64
Day care	1	12
Alternative therapy	1	12
Personal qualities	1	12
Total	**8**	**100**

God as Receiver

The final Receiver for Patient as Sayer in the interview data is God. This particular addressee was not found within the advice data and so may be worth consideration. God accounts for 10% of Patient's receivership and although never mentioned, it is clear from the context that God is the intended and understood addressee of these verbal processes. Examples include 'one has to pray for this belief', 'I pray for a deepening of faith all the time', 'I pray for the trust and belief that this life is a prelude to the afterlife and that the afterlife is what counts' and 'I pray for the grace to believe in it'. Such examples introduce a dimension to the interview Patient which is less evident and far more generalised in the advice data. The presence of such processes can be taken as indicative of the faith convictions of certain Patients and their willingness to discuss them, as well as the emphasis placed upon this as an aspect to consider in care and treatment planning within terminal illness (Smith et al., 1983-1984; Leung et al., 2006). An overview of the topics identified for verbal messages to God is provided below.

Table 111: Overview of Topics for Patient as Sayer and God as Receiver in Interview Data

Topics	No	%
Belief	3	30
Faith	2	20
Trust	2	20
Grace	2	20
No fear	1	10
Total	**10**	**100**

To conclude this section on verbal processes for Patient as Sayer, there are far fewer examples of verbal processes for Patient within the interview data than in the advice data. In terms of the interview Patient's Receivers, there is a larger proportion of talk directed towards professionals. This may partly be due to the fact that this Patient is engaged in an extended verbal exchange within the interview and therefore the numbers could be enhanced by the fact that the interviewer is also a medical professional. However, this in itself does not fully account for the increased number as several of the processes included are reported and take place outside of the interview. A possible explanation is that communication with professionals is a significant part of the interview Patient's experience and that although verbal processes may not be the largest process type, professionals are the most likely Receiver within these processes. This underlines the importance of communication between both parties as an important aspect of the Patient experience and the doctor-patient relationship (Silverman, 1987; May, 1995; Ong et al., 1995; Deans, 2004; Vegni et al., 2005; Jadad et al., 2006).

As mentioned previously, Patient as Sayer to Others bears some similarities to the advice data in terms of certain topic areas. However, the interview data differs mainly in that there are far fewer instances of verbal processes directed towards children and those which do appear emerge as more patient-specific than guideline-adherent. This suggests that the reality of Patient's experience of disclosing their cancer diagnosis to their children differs from that set out in the

clear and ordered guidelines of the advice data and approaches may vary depending upon the ages of the Receivers (Koocher, 2010).

Regarding other Patients as Receivers, there are general similarities with the advice data. However, the Patient interview introduces a new Receiver in the form on God. Although it is possible that this can be explained by the religious convictions of individual patients rather than all Patients included in the interview group, the 'presence' of God within interview data may be noteworthy because this does not, and probably would not, appear in the advice data. Religious references do appear in the advice data but are made in only the most general of ways, usually in relation to end-of-life wishes in mental processes rather than verbal processes. Anything more specific to a particular god or religion might be considered too prescriptive within the advice data. In contrast to this, the interview Patient introduces a relationship of near-dialogue between Patient and God. Although Patient is Sayer and God is Receiver and so it is not indicative of a two way conversation, this nonetheless introduces a new representation and relationship which is not evident or explored in this way within the advice data.

Finally, the following table provides a more comprehensive overview of topics for Patient as Sayer in relation to verbal processes with all and no Receivers in the interview data.

Table 112: Receivers and Topics to Patient as Sayer in Interview Data

Receiver / Topic	Professionals	Friends & Family	Children	Patient	God	No Receiver	**Total**
Illness	15	3	6	5		1	**30**
Treatment	15	6	2	1		1	**25**
Feelings, emotions	3				10		**13**
Diagnosis			8				**8**
Help/care/support	5	1		1		1	**8**
Prognosis	4	1				3	**8**
Health state	3					1	**4**
Afterlife	2					2	**4**
Communication						3	**3**
Death	1	1					**2**
End-of-life choices	2						**2**
Patient status	1						**1**
Nurses	1						**1**
Doctor-Patient r'ship	1						**1**
Place in the world	1						**1**
Personal qualities			1				**1**

5.6 Patient as Actor + Inanimate Goal in Interview Data

There are 100 instances of the interview Patient acting upon an inanimate Goal and this total is notably lower than the 150 examples found for the advice Patient. These can be divided between 'intentional' or 'involuntary' material processes of 90% and 10% respectively and this follows a similar pattern of distribution to that established in the advice data. The smaller category is outlined below in terms of the typical processes and Goals for the interview Patient with examples such as 'I'm still building up this fluid'. These are often related to things which Patient receives such as help, strength and comfort.

Processes	**Goals**
Get 7	Love 3
Absorb 1	Comfort
Build up 1	Strength
Pass on 1	Help
	A reply
	The news
	Fluid
	Genes

Fig. 50 Patient as Actor + Inanimate Goal in Advice Data: typical involuntary processes and Goals

The group of intentional processes is considerably larger and, similarly to the advice data, includes a diverse range of processes, several of which appear only once. However, it is possible to group together certain processes on semantic grounds. The table below lists such examples which appear a total of 5 times or more, with those in bold indicating a degree of dominance within the semantic set.

Patient as Actor + Inanimate Goal in Intentional Material Processes

Typical Processes:

put/get in order/throw away/clear/sort 10
do/have done 10
take/use/spend 8
find/find out/read/look at/research/refer to 8
write/sign 5
get (obtain) 5

Fig. 51 Patient as Actor + Inanimate Goal in Interview Data: typical intentional processes

An initial observation is that no obviously medical processes appear within this set but end-of-life activities such as 'we put things in order for my wife', mirroring a similar feature of the advice data when considered at the level of process. However, more can be revealed by considering material processes in combination with their inanimate Goals.

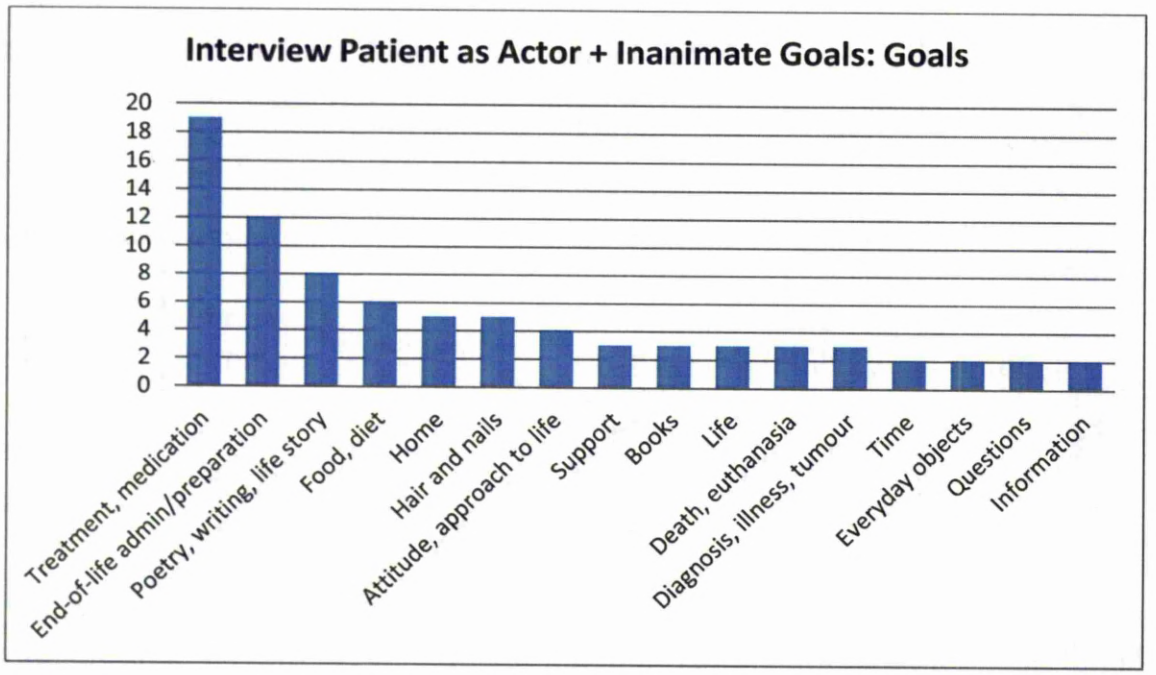


Fig. 52 Goals for Patient as Actor + Inanimate Goal in Interview Data

The three key groups of Goals which emerge from these processes relate to treatment, end-of-life administration and preparation and written texts such as

poetry and life stories. Each of these major sets will now be considered in turn in combination with their related processes. The first of these relates to treatment Goals and processes and accounts for 23% of inanimate Goals. Examples include 'me balancing one drug against the other', 'I take pain killers all the while', 'I'll get morphine' and 'I was able to hire one (a TENS machine) from the local pharmacy'. As these examples show, these treatment processes tend to relate to pain management, rather than treatment as cure. It may also be worth noting that not only is this the most common type of inanimate Goal for the interview Patient, it is a type of Goal which did not appear in the key Goal types for the advice Patient. Therefore, this indicates that the interview Patient is actively engaged in the management of their symptom and pain management (Gaston-Johannsson et al., 1990; Breibart and Payne, 2000; Steinhauser et al., 2001) and quite possibly to a greater extent than is suggested by the assumptions of the writers of the advice data.

A further category of Patient's inanimate Goals can be grouped together within the domain of end-of-life preparations and administration. These involve Patient engaging in both administrative and practical activities such as 'we've signed the documents to say that I don't want to be resuscitated', 'We've brought out a draft plan of a memorial service', 'getting one's address list in order' and 'I've left my body to anatomical science'. In this respect the interview Patient is represented as devoting 15% of their inanimate Goal directed activity towards Goals such as wills, taxes, address lists and financial record. Evidently, the domain of end-of-life preparations is one of significance for the interview Patient and they are five times more likely to engage in this type of material activity than the advice Patient. On the basis of this comparison, it can be argued that the interview Patient's inanimate Goal related activity indicates a greater involvement in the bureaucracy of dying.

This can be read as an indication of Patient's financial concerns (Townsend et al, 1990) and their desire to alleviate them. It may also be regarded as a manifestation of Patient acting within a context of 'open awareness' of death (Glaser and Strauss, 1965) and 'acceptance' (Kübler-Ross, 1973; 1981) without which such tasks are

unlikely to be undertaken. Moreover, acting upon Goals such as financial records and funeral plans are also examples of Patient being 'able to retain control of what happens' and 'be able to issue advance directives that ensure wishes are respected' (Johnston, 2004c, p129) which function as a Patient coping strategy and method of ensuring a 'good death' (Ellershaw and Wilkinson, 2003).

The third key type of inanimate Goal relates to texts such as poetry and life stories. Examples can be found in 'I could do poetry', 'I was writing my life story' and 'Writing reminiscences of early years'. Again, this is unlike Patient in the advice data whose inanimate Goals when texts, tend to be in a receptive process type such as reading, compared to the more productive nature of the interview Patient's processes as Actor upon inanimate Goal. Furthermore, for the interview Patient they involve acts of creating, and leaving behind a narrative. They can also be considered as significant examples because whereas the literature often focuses upon Patient narratives of illness (Kleinman, 1988; Greenhalgh and Hurwitz, 1998; 1999), these constitute Patient narratives of living whereby the interview Patient positions themselves within a different narrative framework, beyond the medical gaze. Such examples of processes and Goals often take place within the context of Special Palliative Day Care and have been analysed as activities which focus upon life whereby 'Patients described how activities such as pottery, flower arranging, and creative writing enabled them to think about something other than themselves and their illness' (Bradley et al., 2010, p1216).

The following types of Goals are less frequent but nonetheless combine to create identifiable groups. The first of these relates to Goals such as meals, foods, and diet, as in 'you don't eat anything that's maybe just got a tiny trace of dairy food in it'. These examples show Patient as actively controlling and modifying their diet in order to improve their health state, as in 'I've cut out so many things that introduce a kind of fog with me'. They also place emphasis upon the relationship between diet, response to treatment and survival rates (Copeland et al., 1977; Ingram, 1994.) A further feature of these instances is that they represent Patient as acting independently of medical advice and on the recommendations of another patient

who had 'really researched this carefully', thereby exploring self-care and acting upon lay theories and experience (Levin et al., 1977; Calnan, 1987; Williams and Calnan, 1996).

The next Goal group, comprising 6%, relates to the home and includes examples of Patient acting upon domestic Goals such as 'I've been mending all the doors' and 'we could sell this place'. These examples touch upon Patient carrying out home improvement tasks on parts of their house and this is framed similarly to the end-of-life administration and preparation, in terms of tasks which Patient is represented as completing before they die. In this respect, they represent domestic unfinished business which Patient is in the process of completing.

A further Goal group appears in equal proportion to home improvement and relates to personal grooming, as in 'then I can just take the rollers out'. Both Goals appear to represent Patient acting outside of the medical gaze, although home improvement can be placed under the umbrella of Patient's 'to do' list and in this sense may be a set of Goals which is influenced by the context of health.

The final type of Goal relates to Patient's approach to life and how it has become transformed by their illness. Examples of this can be found in 'you have to change your attitude really' and 'one has to change one's whole approach to life' and account for 5% of Patient's inanimate Goals, demonstrating the extent to which a diagnosis of cancer necessitates an overhaul of Patient's world view (Armstrong-Coster, 2004).

The remaining Goals can be summarised in the table below, with each one accounting for 4% of the interview Patient's inanimate Goals. One observation to note is that illness, death and life appear as Goal with equal frequency and that the overall balance of activites in this lower frequency subgroup is more inclined towards life and living related Goals than illness and death.

Goal	Example
Support	I got Attendance Allowance
Books	some books you read them
Life	you live your life
Death	We don't treat it (*death*) as part of the process of life
Illness	The minute I found that third tumour

Fig. 53 Lesser Goals for Patient as Actor + Inanimate Goal in Interview Data

To conclude this section, it can be seen that the interview Patient inhabits a somewhat different landscape of Goals and material processes, both in quantity and type, when compared to the advice Patient. Key processes from both data sets are outlined below and show that the interview Patient is more actively involved in processes which relate to end-of-life preparations than the advice Patient who engages more in illness and treatment research. This is indicative of the interview Patient's more evident 'open awareness' of death and dying than the advice Patient.

Advice **Patient as Actor + Inanimate Goal in Intentional Material Processes**	**Interview** **Patient as Actor + Inanimate Goal in Intentional Material Processes**
use/spend/ take 22 **find out/find/**read/look at/research **19** set/make/organise/reorganise 8 make/take/leave/make up/choose 8 make/write 7 get (obtain) 6 contact 5 put/sort 5	**put/get in order**/throw away/clear/sort **10** do/have done **10** **take**/use/spend 8 **find**/find out/read/look at/research/refer to 8 write/sign 5 get (obtain) 5

Fig. 54 Patient as Actor + Inanimate Goal in Advice and Interview Data: typical intentional processes

An overall summary of the interview Patient's activity as Actor + inanimate Goal can be seen in the table below, with the proportional balance of intentional, involuntary and creative processes broadly the same as in the advice data.

Material Process Type	Typical processes	Goals
Intentional	take, use, balance, hire, try out, buy, get	treatment, drugs, painkillers, medication, medical equipment, medical services, nursing care
	sign, put in order, write, do, bring out, leave	documents, papers, address list, will, taxes, a draft plan of memorial service, my body
	do, write, bring	poetry, my life story, creative writing, reminiscences
	make, eat, cut out, improve	meals, certain foods, fruit and vegetables, diet, dairy products
	sell, buy, mend	this place, a smaller place, doors, windows
	do, take out	nails, hair, rollers
	change, find	approach to life, outlook on life, way of thinking, attitude
Involuntary	get, absorb, build up, pass on	love, comfort, strength, help, a reply, news, fluid, genes
Creative	build up, bring out, write (down), make, do	fluid, a draft plan of a memorial service, reminiscences, hopes, meals, poetry, life story, a list of questions and points

Fig. 55 Overview of Patient's Participation as Actor + Inanimate Goal in Interview Data

Overall, the interview Patient as Actor + inanimate Goal participates in actions which tend to occur where the Patient possesses a degree of death awareness and acceptance. There is a clear focus upon actions which precede death and are designed and undertaken in order to ensure that Patient's wishes are followed and the burden of responsibility upon their family is reduced. This is somewhat in contrast to the advice Patient who, although engaging in some similar activities, is more involved in researching their illness and developing care plans. Therefore, the

interview Patient represents their experience of living with terminal illness somewhat differently from that assigned to the advice Patient and in placing emphasis upon actions which help prepare for their death, represents their experience of approaching dying in a way which can be regarded as showing greater awareness, autonomy and initiative than evident for the patients of the past (Field, 1996).

5.7 Patient as Goal in Interview Data

The next participant role for the interview Patient is Goal, comprising 6% of Patient's overall participation, which is in accordance with the percentage within the advice data. This group represents Patient in a participant role of low dynamic value, being acted upon by other entities. Of the 83 examples within this group, only two were found to be involuntary, involving the illness and Patient as Actor. These examples are 'you got something different testing you' and 'the circumstances that I had found myself in very unexpectedly'. The remaining processes in which Patient is Goal were all found to be intentional and involve a range of Actors which are summarised below.

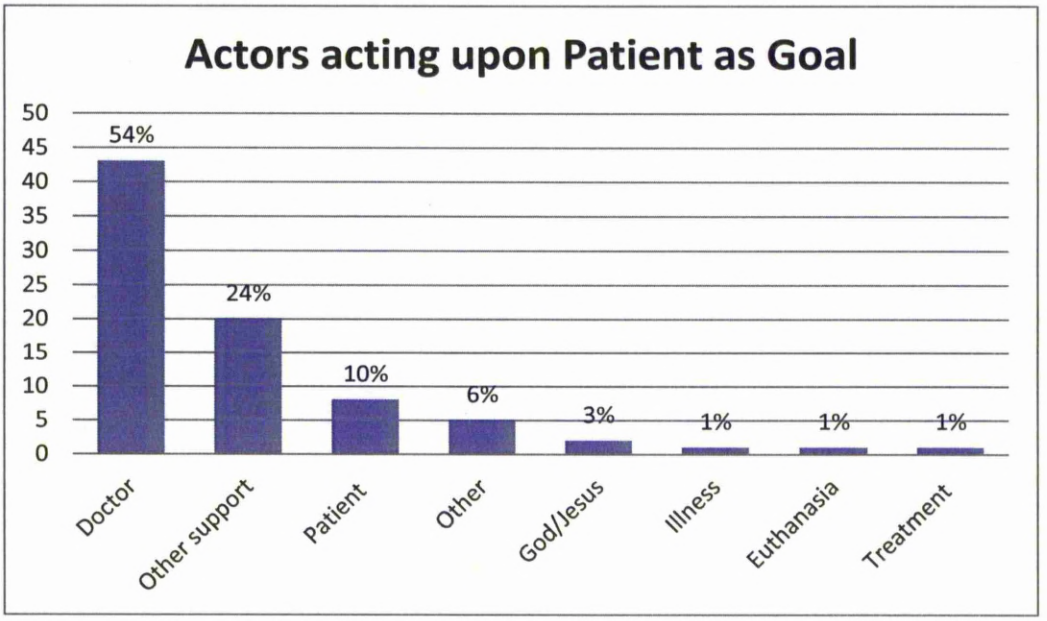


Fig. 56 Actors acting upon Patient as Goal in Interview Data

In comparison with Actors acting upon the advice Patient, this group presents a wider range of Actors with the introduction of additional Actors such as God and Jesus, the illness and euthanasia as Goal. The overall pattern of distribution is similar for both the advice and interview Patient in that over 50% of activity directed upon Patient as Goal is carried out by Doctor. Variations do emerge and these can be found in the higher incidence of Other Support and Patient as Actor

and lower participation of Other and treatment as Actor acting upon the interview Patient. Each of the key types of Actors will be summarised below with supporting examples from the data.

The largest category of Actor acting upon Patient as Goal is Doctor, accounting for 54% of the complete group. This finding is to be expected although the nature of the processes involved can reveal more about the type of activity in which Doctor engages when acting upon Patient, as shown below.

Table 113: Types of Processes for Doctor as Actor acting upon Patient as Goal

Doctor as Actor	No	%
Treatment	24	56
Admin/admissions	12	28
Help	7	16
Total	**43**	**100**

Similarly to the advice Doctor, processes relating to treatment form the most significant category, with examples such as 'the majority of women that are treated for breast cancer' and 'they scanned me'. These examples represent Patient being acted upon by Doctor in a predictable and traditional configuration for treatment processes and it is not surprising that this forms the largest type of activity directed upon Patient.

The second most common type of process, however, does not emerge within the advice data and so its presence and quantity may be noteworthy. This type of activity relates to processes of admissions and administration such as 'I've been transferred to the care of the Palliative Care Team' and 'he arranges for me to be admitted in an emergency' which represent Patient as a case within the wider administrative process which surrounds the medical process. The final, and smallest, category of activity directed upon Patient as Goal by Doctor as Actor

relates to more general help and assistance, as in 'all those that really have helped me'. In brief, the interview Patient is acted upon by Doctor in treatment, administrative and helping processes.

The second most frequent type of Actor acting upon Patient is Other Support. This group includes social workers, therapists and hairdressers. Examples include 'the Social Services are looking after them', 'he (the reiki therapist) doesn't touch me' and 'she washes my hair'.

Such activity can be summarised according to the nature of the action upon Patient which shows that the most apparent type of action upon Patient as Goal relates to beauty therapy and treatment.

Table 114: Types of Processes for Other Support as Actor acting upon Patient as Goal

Other support	No	%
Beauty treatment	12	60
Help	3	15
Look after	2	10
Take out	1	5
Touch	1	5
Recycled	1	5
Total	**20**	**100**

This finding may not necessarily have been predicted but does accord with related findings for Patient as Actor + inanimate Goal. It is also possible evidence of the interview Patient representing their experience of being acted upon as inclusive of processes other than those of a strictly medical nature. This presents a distinct contrast in comparison with the advice data in which Patient is acted upon by Other Support in medical or medically related processes. A further point of contrast is between the typically negative experience of treatment processes directed at

Patient as Goal and this more positive experience of beauty treatment directed upon Patient in an attempt to counteract some of the negative aspects of medical treatment such as hair loss and nausea.

In 10% of instances in which Patient is Goal, they are also acted upon by Patient as Actor. Examples include 'you test your brain' and 'I've left my body to anatomical science'. Although no obvious pattern emerges due to low incidence, it may be of some note that this configuration is more frequent than Other acting upon Patient. This suggests that activity directed upon the interview Patient is more likely to be self-directed than enacted by friends and family, whereas the reverse is true for the advice Patient.

Other as Actor is responsible for 6% of processes in which Patient is Goal. Examples include 'some of my friends helped take me down for my chemotherapy' and 'somebody wanting to get rid of their relatives'. Overall, the tendency is towards processes of helping and supporting and this pattern is partly true of other Actors acting upon Patient as Goal, as summarised below. It may also be of note that the interview Patient presents very little grammatical evidence of being acted upon by their illness.

Table 115: Minor Actors acting upon Patient as Goal

Actor	Example
God/Jesus	and his son redeemed us all
Illness	you got something different testing you
Euthanasia	euthanasia to help me
Treatment	Fybogel which is supposed to help you a bit too

To conclude, the interview Patient as Goal bears some similarity with the advice Patient in terms of processes of medical treatment, care and support. A further

point of similarity is the incidence of role sharing whereby the action is carried out by more than one possible entity, as in 'all those that really have helped me', which can refer to Doctor, Others and Other Support. In addition, a new type of activity emerges from the interview data which is connected with the administrative and bureaucratic nature of the medical domain. Finally, in terms of features at variance with the advice Patient, the most notable emerges as Patient's non-medical activity when taking the role of Goal which is 20% higher for the interview Patient and indicates that the interview Patient is more likely to be the focus of non-medical activity in contrast to the more typical and predictable configuration found in the advice Patient.

Table 116: Types of Activity for Patient as Goal in Interview and Advice Data

	Advice		Interview	
Types of Activity	**No**	**%**	**No**	**%**
Helped/cared for etc	35	57	13	16
Being treated physically/medically (before and after death)	17	28	29	35
Non-medical but actions related to illness & treatment	5	8	8	10
Being treated in general (how people treat/behave towards you)	3	5	3	3
Non-medical action	1	2	18	22
Administration and admissions			12	14
Total	**61**	**100**	**83**	**100**

Finally, it is possible to calculate the dynamic value of Patient in the interview data with the application of weighting the participant roles for Patient. The following table shows that Patient's participation as Actor, Senser and Sayer have the greatest influence upon the level of dynamism in the interview data. Furthermore, the total score for the interview Patient is noticeably lower than for the advice Patient.

Table 117: Overall Participation of Patient in Participant Roles in Interview Data in Order of Frequency

ROLE	Weighting	No	Score
Initiator	+3	4	12
Attributor	+3	6	18
Actor + animate goal	+2	19	38
Actor + inanimate Goal	+2	100	200
Actor – goal or + scope	+1	198	198
Behaver	+1	15	15
Sayer	+1	105	105
Senser	+1	337	337
Token	0	8	0
Value	0	15	0
Carrier	0	285	0
Beneficiary	-1	33	-33
Phenomenon	-1	28	-28
Scope	-1	1	-1
Goal	-2	83	-166
Receiver		27	
Verbiage		7	
Target		2	
Attribute		2	
Existent		7	
Circumstance		97	
Total		**1379**	**+696**

Chapter Six: Conclusion

Having described and discussed the analytical findings, it is now possible to draw some more general conclusions regarding the representations of Patient within the advice and interview data. Therefore, this final chapter sets out to outline key findings which have emerged from the comparison of the advice and interview data. In addition, possible limitations of the study will be addressed as well as future recommendations. Finally, it is hoped that the overall contribution of this study will be underlined, along with practical suggestions regarding the possible applications of the findings of the current study to online advice texts.

To return to the original research questions and hypothesis, the aim of this study has been focus on the voice of the terminally ill cancer patient and to examine how language is used by both medical experts and expert patients to describe medical experience and represent the experience of living with terminal cancer. A further aim has been to identify similarities as well as differences between these two sources in terms of the transitivity patterns which emerge from the analysis of both advice and interview texts. One initial assumption has been that the advice texts might be taken as more indicative of the 'voice of medicine' and the patient interviews the 'voice of the life world' (Mishler, 1984), and that in this way it may be possible to compare grammatical patterns, the assumptions and experience encoded therein and whether the patterns and representations in the two data sets correspond with each other. Regarding the hypothesis, it was originally anticipated that owing to the differing sources, there would be a noticeable degree of difference between the patterns found within the two sets of data.

In order to compare key findings across both data sets, two of the most common overall participant roles will be considered and compared. Rather than explore every possible point of accord and divergence, these participant roles will be mined and explored in order to highlight and summarise particular key findings outlined in the previous two chapters. The first of these relates to Patient as Carrier.

Patient as Carrier

Generally the advice Patient takes the role of Carrier with slightly greater frequency than the interview Patient. However, the general pattern of distribution across types of relational attributive processes is quite similar in that intensive qualities are more common for both Patients. It may be of interest to explore this group further because, as mentioned previously, the qualities or attributes with which Patient is represented are 'ascribed' rather than 'given' can reveal something of the choices made by the advice writers in comparison to those ascribed by the interview Patient. It is also a possible way of comparing the advice writers' view of Patient with the interview Patient's self-perception.

Table 118: Types of Attributes and Distribution across Interview and Advice Data

			Interview		Advice	
Type	**Describing**	**Example**	**No**	**%**	**No**	**%**
Intensive	qualities	I am **open-minded**	159	56	219	71
Possessive	ownership and belonging	you have **a family**	96	34	81	26
Circumstantial	location, time, quantity, matter	I was **in a wheelchair**	30	10	11	3
Total			**285**	**100**	**311**	**100**

A closer consideration of the most common group of relational attributive processes for Patient as Carrier tells us something of both views of Patient in terms of the qualities ascribed. Again, it emerges that states with mental overtones are the largest type of attribute for both Patients and that the types of qualities in both cases follow a similar pattern in terms of frequency, with health states being less common than states with mental overtones, as shown in the table below.

Intensive Attributes

Table 119: Types of Intensive Attributes and Distribution across Interview and Advice Data

		Interview		Advice	
Type	**Example**	**No**	**%**	**No**	**%**
States with mental overtones	One can be **afraid** of a painful death	58	35	78	36
Health states	I hadn't felt **ill**	44	27	62	29
General States	I'm now **eighty-five**	41	25	67	30
Personal qualities	I'm always **cheerful**	22	13	12	5
Total		**165**	**100**	**219**	**100**

The pattern of general similarity continues if the findings are mined further to explore the most common type of attribute which relates to states with mental overtones. This reveals some variation in that not all comparable mental processes can be found in the intensive attributes ascribed and self-ascribed to Patient, with the absence of desideration and perception. However, in those which do appear, again there seems to be a similar pattern of distribution in favour of attributes related to mental states of emotion over cognition.

Table 120: Patient's Intensive Attributes with Mental Overtones in Interview and Advice Data

		Interview		Advice	
Type	**Example**	**No**	**%**	**No**	**%**
Emotion	you seem to be feeling more down than ever	41	75	67	86
Cognition	you may become confused	14	25	11	14
Total		**55**	**100**	**78**	**100**

This sample comparison of one of the most common participant roles for Patient in both data sets suggests that on the basis of Patient as Carrier in both interview and advice texts, the expectation of more difference than similarity does not appear to be the case thus far. However, this is based upon only one participant role and it is necessary to consider additional prominent roles before any firmer conclusions can be drawn. In order to do this the participant role of Senser will also be explored.

Patient as Senser

The following two tables show that overall there appears to be generally more agreement than divergence in terms of mental activity. Both types of Patient appear more commonly in processes of cognition and least commonly in processes of perception. There is a degree of difference in that the interview Patient emerges as more likely to engage in processes of emotion than desideration whereas the reverse is true of the advice Patient. This suggests that the advice writers represent the Patient as more inclined to 'wanting' and 'wishing', whilst the advice Patient in more inclined towards processes of 'feeling'.

Table 121a: Patient as Senser in Interview Data

Process Types	No	%
Cognition	213	63
Emotion	62	18
Desideration	50	15
Perception	12	4
	337	**100**

Table 121b: Patient as Senser in Advice Data

Process Type	No	%
Cognition	116	54
Desideration	56	26
Emotion	28	13
Perception	16	7
	216	**100**

Moreover, to gain a more detailed comparison of both Patients' mental processes, it is necessary to consider each type of mental process in turn with their related Phenomenon.

Cognition

The following table summarises key similarities and differences in both data sets according to the domains of experience and Phenomenon. Shaded areas indicate absence and braces indicate overlap. What becomes apparent when these cognitive processes are viewed in the context of the accompanying Phenomenon is that illness and dying/end of life are the core areas which both advice and interview Patients think about. On the other hand, there are a number of areas which are more particular to each Patient type and whilst the interview Patient thinks about religion, people and communication, the advice Patient tends to think about living, time and information. A simple way of perhaps explaining this might be that because mental processes are internal, less tangible or evident they may be thus more difficult for advice writers to anticipate. It does, however, present a possible point of interest for advice writers in accessing Phenomenon which they might otherwise find harder to discover. Examining what the interview Patient is thinking about may offer some possible insight into the concerns of real patients.

Table 122: Comparison of Phenomenon According to Patient's Domains of Experience in Processes of Cognition in Interview and Advice Data

Phenomenon	Interviews		Advice	
	No	%	No	%
Health, illness, medicine	76	44		
Illness			18	28
Life and death	62	36		
Death/End-of-life			11	17
Living			11	17
Information			11	8
Time/the future			5	8
Religion and beliefs	13	8		
People, personal qualities	10	6		
Communication	10	6		
Communication about illness			5	8
Support			3	5
Totals	**171**	**100**	**64**	**100**

Emotion

The following table provides an overview of Phenomenon in Patient's processes of emotion in both the advice and interview data. Again this suggests key similarities regarding the issues which both types of Patient respond to emotionally such as their illness. It may also be worth noting that matters relating to life and living are present for both whereas death and end-of-life are present for the interview Patient but not the advice Patient. This may be a further example of a matter which concerns real patients, on which they may require some guidance from the advice texts.

Table 123: Comparison of Phenomenon According to Patient's Domains of Experience in Processes of Emotion in Interview and Advice Data

Phenomenon	Interviews		Advice	
	No	%	No	%
Illness	18	37	6	20
End of life, death	11	22.5		
Life, activities	11	22.5	9	31
Emotions, belief, religion	4	8	1	3
People	3	6	9	31
Care	2	4	1	3
Problems			1	3
Relationships			1	3
Reactions of others			1	3
The future			1	3
Total	**49**	**100**	**30**	**100**

Desideration

Engagement in processes of 'wanting' was more common for the advice Patient than the interview Patient and the table below offers an overview of Phenomenon and domains of experience within which these 'wants' tend to appear. These findings also indicate that the key context within which both Patients engage in processes of wanting relates to end-of life matters. It may be of some interest that this is the only Phenomenon and domain of experience which is common to both the advice and interview Patient and could therefore be considered as central to

patient wishes in this context of health. In terms of differences, one area which is evident for the interview Patient but not the advice Patient relates to wishes concerning other people and their personal qualities.

Table 124: Comparison of Phenomenon According to Patient's Domains of Experience in Processes of Desideration in Interview and Advice Data

Phenomenon	Interviews		Advice	
	No	%	No	%
End of life	20	46	21	34
Treatment, care	13	30		
Care, support, treatment			12	19
People, personal qualities	8	19		
Living	2	5		
Living/activities			16	26
To discuss illness			9	15
Ask for/get info about illness			4	6
Total	**43**	**100**	**62**	**100**

Perception

The final type of mental process to be compared for both Patient types is that of perception. In both cases it is the least common type of mental activity and both engage in the perception of their illness and symptoms. In terms of similarity, this places Patient's perceptive activity firmly within the medical gaze and biomedical Phenomenon. However, this Phenomenon is the only example which is common to both Patient types and there appears to be a greater degree of diversity of Phenomenon in this group of processes than the previous three.

Table 125: Comparison of Phenomenon in Processes of Perception in Interview and Advice Data

Phenomenon	Interviews		Advice	
	No	%	No	%
Illness/symptoms	4	34	3	20
Treatment	3	26		
Medical equipment	1	8		
Nurses' comments	1	8		
Complications of euthanasia	1	8		
Patients	1	8		
TV programmes	1	8		
Information load			3	20
Hallucinations			2	12
Family and friends/people			2	12
An urge to talk			2	12
Conversation (sound/words)			2	12
Patient information guide			1	6
Stories about treatment			1	6
Total	12	100	16	100

Having explored the two most common participant roles for Patient overall and compared them across the interview and advice data, it is worth relating certain key findings to the original hypothesis in order to examine whether it can be confirmed or should be rejected according to the key findings.

The original hypothesis as put forward at the beginning of this thesis was that there would be clear differences in the grammatical patterns within the advice and interview data and the anticipated outcome was that overall more differences than similarities would emerge from the grammatical patterns found in the analysis. However, in light of the findings and the comparison of these findings in relation to two key participant roles within both data sets, the overall conclusion is that there seem to be more similarities than differences, particularly when comparing the general transitivity profile of Patient in both data sets. Where differences exist, these tend to be at the level of related participants or transitivity slots such as Attribute or Phenomenon and particular groupings of these such as the personal qualities ascribed to by the interview Patient being more frequent and more likely

to be positive than those ascribed by the writers of the advice texts. A lower level but not insignificant difference such as this could suggest that the interview Patients view their personal qualities more positively than the writers of the advice texts appear to.

One further notable and unexpected finding has been in the level of dynamism found in the advice and interview Patients whereby the advice Patient emerges as more dynamic than the interview Patient. However, bearing in mind that the advice Patient can be regarded as a creation of the advice writers, it should be noted that this finding may be more an indication of the advice writers' assumptions about patients than representative of patients themselves. This may also suggest that the interview Patient's experience of living with terminal cancer is one in which they feel less powerful and in control of than the representations presented by the writers of the advice data. The table below presents the combined dynamism scores for both the advice and interview Patient. Whilst the overall score suggests that the advice Patient is represented as more generally more dynamic, there are also certain participant roles in which the interview Patient achieves greater dynamism. For example, at a glance it can be seen that the advice Patient's greatest degree of dynamism is achieved in the role of Actor + inanimate Goal whereas the interview Patient's greatest dynamism is in the role of Senser. This represents the interview Patient as generally more dynamic than the advice Patient in terms of 'thinking and feeling' whilst the advice Patient is more dynamic in terms of 'doing'. An overview of the Dynamism distribution and scoring for both Patient types can be found below.

Table 126: A comparison of Dynamism Scores for Advice and Interview Patient

	Advice			Interview	
Role	**No**	**Score**	**Weighting**	**No**	**Score**
Carrier	311	0	0	285	0
Actor – goal or + scope	279	279	+1	198	198
Senser	216	216	+1	337	337
Sayer	181	181	+1	105	105
Actor + inanimate goal	150	300	+2	100	200
Goal	76	-152	-2	83	-166
Circumstance	68			97	
Behaver	36	36	+1	15	15
Beneficiary	27			33	-33
Receiver	26			19	38
Actor + animate goal	17	34	+2	6	18
Attributor	10	30	+3	6	18
Phenomenon	8	-8	-1	28	-28
Target	5			2	
Attribute	5			2	
Initiator	2	6	+3	4	12
Scope	2	-2	-1	1	-1
Token	1	0	0	8	0
Value	0			15	0
Existent	0			7	
Total	**1420**	**+920**		**1379**	**+696**

The Voice of the Patient

To return to a central aim of this study, the analysis of both data sets has revealed a Patient who, in both advice and interviews, is somewhat removed from the former, passive patient of the biomedical and paternalistic models. The overall emerging Patient is more informed and involved in the context of health and presents a departure from previous models of patient behaviour, in the direction of a more patient-centred and patient-led arrangement, in which they operate and represent their experience beyond the parameters of the traditional patient role of reporting symptoms in compliance with doctor's requests. The results of the transitivity analysis present a patient who is emotionally literate, medically literate, an active

researcher, a doctor-patient, and a co-doctor patient. Comparisons between advice and interview data also reveal a possible process of training or priming in which the trainee/trained patient and doctor appear to be merging roles to become 'partners in treatment' (Killeen, 2004, p203) and collaborative problem-solvers (Young and Flower, 2001). Other dimensions to Patient which have emerged in the analysis relate to the compliant patient who tends to follow the doctor's advice, compared to the more autonomous patient who will research alternative therapies and investigate lay theories as well as medical treatments. In addition, there are traces of the client-patient who critically evaluates the medical services they receive. A key point to bear in mind when considering patient types is that no one type fits any given patient exclusively and that the analysis reveals multiple aspects, even within individual patients.

Such a varied spectrum of patient roles and experience may add weight to the need for a patient-centred approach to health care in which the practitioner 'seeks an integrated understanding of the patient's world – that is, their whole person, emotional needs and life issues' (Porter, 2004, p88). Based upon the analysis of processes, roles and emerging topics for the interview and advice Patient, it can argued that both data sets address a wide range of contexts and concerns and so appear to take a suitably patient-centred approach to describing the experience of living with terminal illness.

For instance, evidence can be found in processes which involve the Patient at work, with their families and engaging in activities other than treatment such as recreational activities within palliative day care. It can also be seen in the extent to which the Patient in both data sets, more so in the interview data, is actively engaged in preparing for their death. This represents the experience of living with dying as one removed from the prior medicalisation of dying (Armstrong, 1987) but closer to a person-centred approach which involves personal choices for the patient within their community (Charlton, 2002). Such activity represents the re-appropriation of dying from the medical to the personal domain via a patient, person and family centred approach.

In theory advice and interviews are two distinct types of discourse. The advice data has been 'cultivated' by professional writers with greater deliberation involved in this type of discourse. It is prepared with due consideration for the target reader, purpose, organisational and language features. In contrast, the patient interview data is more spontaneous and 'naturally occurring' discourse and whilst the content may have been considered, it is unlikely that the interviewees considered their language choices to the same degree as the advice site writers. Given this fundamental difference in source, the similarities between the two are perhaps noteworthy.

Such similarities may be partly due to the informed Patient absorbing and using more medical language but also due to the advice data, again perhaps more deliberately, modifying their language to assimilate features of spoken discourse and patient talk. In essence, both appear to be appropriating elements of the language of the other in order to concord and essentially speak the same language, rather than, as could be argued in the past, speaking different languages. This indicates that language and communication are seen as central to medical encounters and the doctor-patient relationship. Furthermore, this study has found the similarities to be evident within the transitivity patterns of the two sources of data.

However, this is not to argue that the Patients in the two data sets are identical and it should be noted that the transitivity patterns found also indicate differences. For example, the interview Patient's transitivity patterns within verbal processes of breaking the news of their diagnosis to others do not fully adhere to the 'model' as set out in the advice data. In this respect, it could be argued that the transitivity patterns suggest that the interview Patient deviates from the recommended model and represents their experience of this scenario differently. This is not necessarily done with explicit awareness of the 'model' found in the advice data, nor is it suggested that this is a reaction against that 'model'. It should be highlighted that assumptions cannot be made that all the interview Patients consult such advice texts. Although it may be likely that some do, and indeed several make reference to

this activity in their interviews, the deviation from the advised 'model' emerges from a more generalised picture and so it is unreasonable to draw a direct correlation between exposure to and deviation from this model on how to disclose your diagnosis to others. What is of central importance to the current study is that certain differences exist between the advice Patient and the interview Patient in terms of how they represent the experience of conducting diagnosis disclosure. This suggests that there are differences not only in how both types of Patient choose to encode this experience but that they do not necessarily conduct or experience this event in the same way.

This can be regarded as an example of how the analysis of transitivity patterns of the interview data can reveal the way in which language is used to describe the interview Patient's experience of living with terminal illness. It is not simply the case that the grammatical choices of the Patient capture their experience but that they also construe their experience, in this case of how the interview Patient chooses to disclose, or not disclose their diagnosis to their children. It may also be that examples within the analytical findings whereby the interview Patient represents their experience differently from the advice Patient may be of interest for the purposes of examining variation or even discrepancies between anticipated experience and lived experience. It can also be argued that the Patient who emerges from the advice data is, to some extent, an idealised patient, based upon the assumptions of the writers about patient experience and with this in mind, it may not be surprising that the assumptions encoded within the grammatical choices of the writers do not always match with the experience of the interview Patients.

Nevertheless, some limitations are evident within the current study and should also be taken into consideration. For instance, the advice Patient should be viewed as a creation of the advice writers based upon their assumptions about the ideal patient, rather than a real Patient and this distinction needs to be maintained in order to avoid the 'fictional' Patient becoming confused with the 'real'. A further possible limitation may be that the interview Patient is only representative of the

type of person who would choose to be interviewed about their experience. This therefore does not include people who have not reached 'acceptance' or 'open awareness' and so in this respect, still represents an ideal patient and the assumptions encoded within their language choices. Therefore, in the same way that medicine has a 'clinical iceberg' (Last, 1963), whereby a significant proportion of illnesses are not reported to the doctor, similarly it may well be the case that an 'experiential iceberg' exists whereby experiences are not reported by patients to patients. By its very nature it is difficult to say what the proportion is and so the findings cannot be taken as representative of all patient experience. Patient participation in a venture such as DIPEx is relatively new and whilst the findings cannot be the grounds for generalisations about all patients, they can perhaps be considered as the basis for tentative generalisations about this new breed of Patient.

In addition, the current findings and conclusions cannot necessarily relate to all patients but should be viewed within the specific context of health of the current study. Thus any observations and conclusions should be confined to the terminally ill cancer patient. In comparison to other types of patient, it should be emphasised that terminal illness is a context in which the patient is given a unique frame of reference which requires a different way of looking at the world and being in the world (Tamura et al., 2006). In order to examine the terminally ill patient's experience of being in the world, patient language choices can reveal much about their representation of the experience of living with dying.

However, a further limitation or issue to be taken into consideration is that the methodological approach has led to a more generalised Patient made up of the combined instances of Patient in the advice and interview data. This has been necessary in order to explore transitivity templates and grammatical patterns at the concordance level. However, this has been at the expense of the individual patient voice and is of particular concern in relation to the interviews which set out to explore individual experience. In this respect, it could be argued that further

research which examines transitivity patterns and templates at the level of individual patients would be a worthwhile endeavour. However, in order to explore wider and more general grammatical patterns and choices, some degree of combining and an overview of analytical findings might also be required.

Regarding the interview data, it is also possible that the chosen grammatical structure of interviewers' questions may indirectly influence the transitivity choices of the interviewee in their responses and this could well be a contributory factor. Whislt it is accepted that this could be the case, in the case of much of the interview data the majority of interview questions are brief, open and tend to elicit a long turn in which the likelihood of adhering closely to the transitivity choices of the interviewer throughout the long turn response may be less likely than with short answer questions in which the interviewer and interviewee share the talking time more equally. An example of the question and answer structures and distribution can be found in a fully transcribed, analysed and marked up interview in Appendix C.

A further area of possible future research might be to compare the grammatical representation of Patient with other entities involved in the context of health such as doctors and family members. Rather than examining the Patient alone, transitivity profiles could be compiled for each of the key entities and comparisons made between them. This could help to build a more complex overview of how those concerned are represented and interact with each other. Previous research has also examined transitivity patterns for patients in advice data across differing health contexts (Driscoll, 2000) and such a comparison would make it possible to identify any distinguishing grammatical features of terminally ill cancer patients in comparison to patients from within a different context of health.

However, the main focus of this study has been restricted to the representation of the Patient experience of living with terminal cancer and as such it has compared two grammatical accounts of the same experience in order to identify possible similarities and differences in these accounts. The fact that the original hypothesis

and has been proved partly wrong and the expectation of more differences than similarities has not been met does not necessarily detract from the outcome and the overall research process involved. To the author's knowledge, this is the first time that such an extensive transitivity analysis has been carried out on patient interviews. In addition, the application of the transitivity system to a corpus which is made up of two rather contrasting written and spoken data sets has entailed certain challenges when applying the same model and analytical tools to more carefully constructed written advice texts and the more naturally occurring spoken interview texts. As a result the contribution of the current study to the field of Systemic Functional Linguistics may be in the careful application and testing of Transitivity upon such data at some length and in some detail. As mentioned previously in the Methods chapter, software does exist which could have been used to process a larger corpus far more quickly and carry out a transitivity analysis. However, the manner in which a manual approach enables the exploration of complexities such as embedded clauses, process blends, joint entities in the same participant roles and implicit entities was felt to be more beneficial. In addition, the current study has also contributed not only to the application and testing of the cline of dynamism, but also certain revisions to it. In this respect, the study might be instrumental in examining the transition from linguistic theory and model to practical application and language analysis and the necessary modifications involved in this process.

In terms of the possible relationship between transitivity and health communication, the contexts of terminal illness and cancer have been explored at length within health communication. However, through the application of transitivity and dynamism, this study may present a way of excavating beneath the surface of language to explore the grammatical patterns through which experience is communicated. This has been done in order to better understand the experience of terminal cancer by exploring the language choices of writers and particularly speakers and how the experience of living with terminal cancer is represented grammatically. Terminal illness is a very particular contextual prism through which

the world is viewed and experienced. Events may be experienced and viewed quite differently from within previous contexts and it can be argued that this presents the ultimate world view we take and one which can challenge or distil previously held assumptions. This frame of reference, therefore, offers a unique framework within which to examine those assumptions, how they are encoded in the lexico-grammatical choices of language users and construe Patient's experience of living with dying.

Potential implications for health advice websites

Finally, there may be more general conclusions and recommendations to be drawn from the study in relation to health advice websites. In the context of health advice, it is not necessarily simply the case that the influence of health advice operates in one direction upon a passive recipient, but the process may have become one of mutual exchange whereby patient experience can potentially influence health advice texts. Certain generic features appear to be mutually exchanged. For example, the transitivity analysis of Patient interviews has shown that there is evidence of Patient taking a more 'medical' role in their experience of living with cancer in processes such as actively researching their illness and treatment. Further examples of the professionalisation of the patient can be found in instances such as the near duplicating of procedural guidelines laid down for trainee doctors on matters such as communicating the news of the diagnosis to others and taking steps to ensure a good death.

More generally, an overall and recurring theme when examining the representations of Patient in the interview and advice data is the extent to which they echo or have come to mirror one other. This is also evident on the basis of text type and format whereby advice websites now incorporate sections on patient experience and patient voices. Although this has become a generic feature of health advice websites, it should be emphasised that this is a relatively recent development and indicates a degree of cross-fertilisation across text types. It has also been the case that observable changes in the generic and language patterns

have been noted during the course of the current study. For example, at the onset in 2005 there were far fewer medical advice websites and amongst the available data at that time, there was certainly far less information regarding terminal illness. Since then, it has become evident that websites are constantly updating and modifying their content, format and language in order to be more user-friendly. In the course of this study it has generally been observed that medical advice websites have evolved to include greater numbers of case studies, patient testimonies and employ more interpersonal features of spoken language in their text. More significantly, the internet is now regarded as a communication tool which can have a direct impact upon patient experience (Ziebland et al., 2004).

In view of observations regarding the format and language of advice websites, it can be argued that there is evidence within health communication practices that patient experience can also have a direct bearing upon the construction of advice texts. It may also be reasonable to suppose that the patient may have greater expertise in patient experience and what it means to be a patient than the doctor. This has become evident by progressive and incremental changes within doctor-patient discourse and the changing roles in terms of interaction and language and has led to the recognition of patient experience as a significant source of meaning (Vanderford, et al., 1997). A step further might be to recognise and further embed patient experience as a common thread throughout advice texts, adopting in part an approach akin to the initiators of the DIPEx website, whereby patient experience is accepted and utilised as a vital component in the delivery of online medical advice.

Possible applications/recommendations for web-based advice texts

Based on the current study, specific language advice might be offered such as the need for advice data to perhaps be more explicit as regards who the specific receivers of verbal messages are in order avoid possible confusion. Although this can be inferred from context when conducting linguistic analysis, it may be

preferable and more useful for the target reader of medical advice texts to have this clearly stated in the verbal process. Furthermore, in instances where the writers are attempting to address a wider range of possible readers such as patients and family members, it may be slightly unclear who the addressee is in that 'people affected by cancer' as target Receiver may not address specific readers or readers' needs sufficiently or with adequate precision.

Similarly, although the 'doctor – patient' can be viewed as a positive manifestation of a more inquisitive and well informed patient who is involved in research and investigation via mental processes of cognition, caution might be exercised regarding the possibility of overburdening a patient with the responsibility of carrying out research and of knowing about their illness in great detail so that they can better inform others via verbal processes. To some extent, there could be some acknowledgement and provision for patients who may lack the inclination or resources to do so by including this reluctance as a legitimate response on the part of the patient.

Furthermore, sections of the advice for terminally ill cancer patients which focus upon processes beyond the medical gaze, such as everyday activities and leisure activities, should be highlighted for inclusion as a matter of course so that such activity remains prominent and the patient's/reader's sphere of experience remains, as far as possible, connected to contexts and activities beyond the medical gaze.

Applications and recommendations for website construction could more generally be taken further still through patient involvement and the recruitment of patients or patient focus groups to review and evaluate advice texts. This could be carried out similarly to the way in which medical experts review advice texts to check for accuracy of medical information. In a similar way, patients could check for clarity and accessibility of information, user-friendliness, ease of website navigation and so on. Finally, whilst it is unlikely that a real patient would want to examine transitivity patterns in the advice texts they encounter, the findings which have emerged from

the current study could perhaps be indirectly checked for validity via the responses of real patients to advice texts in broader terms such as evaluating the appropriacy of the effect upon the reader and end-user, by eliciting reader response to the advice text according to statements such as 'I feel that the writer is speaking to me' or 'This adequately describes my reaction to my diagnosis'. In other words, patient advice texts would not simply be influenced by patient experience but patients could also be in a position to take a more direct and active role in the language choices and construction of health advice online.

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Appendix A

Sample Data

Interview LD26

Age at Interview: 75
Sex: Female
Age at Diagnosis: 74
Background: Orthoptist (retired), widow, 4 children
Brief outline: Diagnosed with colorectal cancer in 2002, followed by surgery and chemotherapy.

She found it hard to tell her children about her illness.

Eventually, I accepted it, but I think the worst part of my illness was having to tell my children. I have four grown up children and nine grandchildren varying from twenty-seven to four. This was the worst thing, I couldn't sleep all night. I can't really particularly remember what he said when he told me I had cancer but I can remember thinking how can I tell the children and I think...

I can't quite remember but I think my son phoned me one day when I was crying. I was having a bad day and so he said, "Oh, what's the matter?" And I said, "I have to tell you, I've got cancer". And he just said, "Oh". I can't remember what he said but he didn't cry or anything. He's now aged forty. So I said, "Well can you break it gently to the rest of the family?" and having four children was a great help because they all came to my house. One from Sweden, one from Cornwall and they were able to discuss the problem and come to terms with it in their own way and so when they came to see me they were sort of cool, calm and collected.

I was also worried about the children thinking that as mother had it, it would be hereditary so I made it quite clear that this is not a hereditary illness, so that was one of the important things about the illness.

Sample Analysis

Living with Dying Interview LD26

Age at Interview: 75
Sex: Female
Age at Diagnosis: 74
Background: Orthoptist (retired), widow, 4 children
Brief outline: Diagnosed with colorectal cancer in 2002, followed by surgery and chemotherapy.

She found it hard to tell her children about her illness.

1 Eventually, I accepted it, but I think the worst part of my illness was having to tell my
senser phen senser phen token value sayer rec..
2 children. I have four grown up children and nine grandchildren varying from twenty-
carrier attribute carrier attribute ...eiver
3 seven to four. This was the worst thing, I couldn't sleep all night. I can't really
behaver senser
4 particularly remember what he said when he told me I had cancer but I can remember
phen ver sayer sayer rec verbiage carrier attrib senser
5 thinking how can I tell the children and I think...
phen senser sayer receiver

6 I can't quite remember but I think my son phoned me one day when I was crying. I was
senser senser phen actor goal carrier behaver
7 having a bad day and so he said, "Oh, what's the matter?" And I said, "I have to tell you,
attribute sayer verbiage sayer verbiage sayer rec
8 I've got cancer". And he just said, "Oh". I can't remember what he said but he didn't cry
sayer verb senser phen behaver verbiage carrier attrib verb say
9 or anything. He's now aged forty. So I said, "Well can you break it gently to the rest of
carrier attrib sayer verbiage sayer ver circ
10 the family?" and having four children was a great help because they all came to my
token value actor circ carrier attrib
11 house. One from Sweden, one from Cornwall and they were able to discuss the problem
actor actor sayer target
12 and come to terms with it in their own way and so when they came to see me they were
senser phen carrier actor goal
13 sort of cool, calm and collected.
attrib

14 I was also worried about the children thinking that as mother had it, it would be
carrier attrib circ senser phen carrier att carr
15 hereditary so I made it quite clear that this is not a hereditary illness, so that was one of
say/attr carr att verbiage token value att carr attrib

Living with Dying Interview LD 26
Concordance of Participants – Entities

Ref	Patient as Actor + animate goal
48/49*	I can't...take them to museums and things.

Ref	Patient as Actor + inanimate goal
57/58	...you've got to make it the way you want it...
73*	I had my appendix out...

Ref	Patient as Actor – Goal or + Scope
35*	I got the MRSA...
48*	I can't run about with children...
49*	I used to (run about children)...
56/57	I can do a bit (of gardening) at a time.
61/62	...Get up and go...
62	...and go (to the toilet)...
62	You can go to the toilet.
63	...I can hardly walk...
63	... by the time I get there (the toilet)...
64	... they can get out of bed...
64/65	...(they can) get to the toilet in time...
65	"Get up and...".
65	"...and go (to the toilet)".
66	...I can't (go to the toilet).
68	... (they just tell) you what to do...

Ref	Patient as Behaver
3	... I couldn't sleep all night.
6	...my son phoned me one day when I was crying.....
63	... I will wet myself by the time I get there.

Ref	Patient as Sayer
1/2*	...(me) having to tell my children.
5*	...how can I tell the children...
7/8	And I said, "I have to tell you, I've got cancer".
7/8*	..."I have to tell you, I've got cancer".
9/10	So I said, "Well can you break it gently to the rest of the family?"
15	...so I made it quite clear that this is not a hereditary illness...
28/29*	I used to say I'm just bed number six...
39*	But the district nurses I'll praise.
62/63	And I said, "Well look, I can hardly walk, I will wet myself by the time I get there".

Appendix B

National Cancer Institute Web site (http://www.cancer.gov/), Taking Time: Support for People with Cancer. 12/19/03. Available at: http://www.cancer.gov/cancertopics/takingtime/page8 . Accessed 12/8/2008.

Living Each Day

actor circ

When you have cancer, living each day to the fullest means:

circ token

carr att actor scope

staying involved in the duties and pleasures of daily life

va..

carr att

returning to work if possible

..l..

actor circ

making plans for the future

..u

actor goal

Is living with cancer the biggest challenge you have ever faced? For most people, it

token value ben tok

actor circ scope actor

is. Dealing with cancer and facing thoughts of death is a life-changing event for

token value

act scope act scope

most people.

ben

"My cancer made me take a closer look at how I spend my days. Realizing

initiator actor scope sen

act goal

that they might be limited, I was determined to make them as good as

phenomenon carr attribute

att'or carr attribute

possible. I vowed to use my time in ways that were good for me or brought

say verbiage

act goal

carr/act att ben

me pleasure."

ben

Try to live each day as normally as you can. Enjoy the simple things you like to do

actor scope circ sen phenomenon

act phen/scope sen/act

such as petting your cat or watching a sunset.

actor goal behaver

15 Take pleasure in big events such as a friend's wedding or your grandson's high
actor goal circ
16 school graduation.

17 Every day brings its own joy. – Spanish proverb

18 Keeping Up With Your Daily Routine

act scope

19 If you feel well enough, keep up with your daily routine. This includes going to
circ act scope carr attrib
carr attrib act
20 work, spending time with family and friends, taking part in hobbies, and even going

circ act goal circ act scope act
21 on trips.

circ

22 At the same time, give yourself time to be with your feelings about cancer. Also, be
act ben goal carr
carr attribute circ
23 careful about acting cheerful when you are not.
attrib
carr attrib circ
carr att
24 Avoiding your feelings may make you feel worse, not better.
attributor carr attribute
act goal
25 (To learn more, go to "Sharing Your Feelings About Cancer.")
sens phen act circ
act goal circ
26 Use these questions to think about how you want to spend your time.
act goal sens phen
act/sen phen goal
27 Who do I like to be with?
phen.. sen ..omenon
circ carr att
28 Who makes me laugh?
init behav
29 How do I want to spend my time?
phen..sen/act ..omen goal
30 What makes me feel happy?
att'or carr attrib
31 What types of things do I enjoy the most?
phenomenon senser
32 What types of things do I like the least?
phenomenon senser

Is there something I want to do that I've never tried?

Fun

Sometimes people with cancer try new, fun things that they have never done before. For instance, have you always wanted to ride in a hot air balloon or go deep-sea fishing? What fun things have you always wanted to try, but have never taken the time to do? A young woman with cancer put it this way,

"*Too often we patients fill up our lives with meaningful activities and neglect the frivolous outlets that keep us sane.*"

Try to do something just for fun, not because you have to do it. But be careful not to tire yourself out. Some people get depressed when they are too tired. Make sure to get enough rest so you feel strong and can enjoy these fun activities.

The journey is the reward. -- Tao Proverb

Physical Activities

Many people find they have more energy when they take part in physical activities such as swimming, walking, yoga, and biking. They find that these types of activities help them keep strong and make them feel good. A bit of exercise everyday:

50 improves your chances of feeling better
goal
carr att
51 keeps your muscles toned
carr att
52 speeds your healing
goal
53 controls stress
goal
54 helps free your mind of bad thoughts
goal
55 Even if you have never done physical activities before, you can start now. Choose
circ act sen/act
actor scope
56 something you think you'd like to do, and get your doctor's okay to try it. You can
phen/goal act goal act
phen/sco sen/act act sc
57 do some exercises even if you have to stay in bed.
scope circ
carr att
58 Start slowly, doing an activity for just 5 or 10 minutes a day. When you feel strong
act act scope circ
carr att
59 enough, you can slowly increase this time to 30 minutes or more. Let your doctors
act goal say receiver
60 and nurses know if you have pain when you do this activity.
verbiage
carr att circ
act scope

61 Working

62 People with cancer often want to get back to work. Their jobs not only give them an
sen/act phen circ act ben
63 income but also a sense of routine. Work helps people feel good about themselves.
goal att'or carr att circ
64 Before you go back to work, talk with your doctor as well as your boss. Make sure
circ say circumstance att'or
act circ
65 you are well enough to do your job. You may need to work fewer hours or do your
carr attrib act scope act sco..
act scope
66 job in a different way. Some people feel well enough to work while they are having
..po circ carr attrib
act circ
carr

chemo or radiation treatment. Others need to wait until their treatments are over.

act circ
attribute carr att

Talking With Your Boss and Co-Workers

say circumstance

"I was nervous about going back to work. A big issue was what to tell my

carr attribute circ value token
act circ ver say rec..

supervisor and co-workers. I knew that they would be supportive, but I was

sen phenomenon carr
..eiver carr attribute

afraid that they would think I was no longer able to do as good a job as I

attribute
sens phenomenon
carr/act att scope
act

used to."

You might find that your boss and co-workers treat you differently than they did

sen phenomenon
actor goal circ
act

before you had cancer. They may say nothing because they don't know what to

say verb circ
sens phen
circ verb say
carr attrib

say and don't want to hurt your feelings. Or they may not know if you want to talk

sens phen
sens phen sen phen
act goal say

about your cancer or would rather just focus on work.

sens phen
circumstance actor circ

If you can, use humor or make a joke. Humor can help break the ice and make

circ act goal act goal actor/att'or goal

people feel more at ease. Let your boss and co-workers know if, and when, you

carr attribute say receiver verbiage
circ sen/say

want to talk about your cancer. You may find that it is easier than you thought it

sens phen
phen circumstance carr attribute
senser phen

would be.

Your Legal Rights

Some people with cancer face roadblocks when they try to go back to work or get
a new job. Even those who had cancer many years ago may still have trouble.
Employers may not treat them fairly because they believe myths that aren't true.
They may believe cancer can be spread from person to person or people with
cancer take too many sick days. Some employers also think that people with
cancer are poor insurance risks.

It is against the law to discriminate against (treat unfairly) workers who have
disabilities such as cancer. These national laws protect your rights as a worker:

The Federal Rehabilitation Act of 1973

The Americans With Disabilities Act of 1990

Most states also have laws that protect the rights of people with cancer. You can
take legal action (sue) if you think that you are not being hired for a job because of
your cancer. Here are some ways to learn more about your legal rights:

Talk with your social worker and ask about laws in your state. Your social worker
can also give you the name of the state agency that protects your rights as an
employee.

97 Contact your state's Department of Labor or Office of Civil Rights.
actor goal

98 Contact your state Representative or Senator. You can find out who represents
actor goal act/sen scope/phen
token
99 your district and how to contact this person by looking on the Internet or at a
circ
value circ act goal actor circumstance
100 library.

101 Visit the Web site for the National Cancer Institute's State Cancer Legislative
actor circumstance
102 Database Program at http://www.scld-nci.net/

103 You may also want to learn about the benefits you can get as a person with
senser phen
goal actor circumstance
104 cancer. One is the Family and Medical Leave Act. This law allows most workers
val token sayer verbiage
actor
105 to take up to 12 weeks of unpaid time to deal with certain family and medical
goal actor scope
106 problems. To learn more, speak with the Human Resource office where you
circ sayer circumstance circ
sen phen act
107 work. You can also contact the U.S. Department of Labor at (202) 693-0066 or
actor goal
108 http://www.dol.gov/.

109 Some people can't return to their jobs because of their cancer. For instance, you
actor circumstance car/act
110 may no longer be able to lift heavy boxes if that task is a part of your job. If you
att goal circ circ
token value act
111 can't do the work you did before, contact your state Rehabilitation Program. Ask
actor goal say
scope
scope act circ
112 about training programs that teach you the skills you need for other kinds of
target
actor ben goal/att carr circ
113 work. To learn more, look under the state government section in the blue
sen ph behaver range
114 pages of your phone book.

115 **Thinking About the Future**
senser phenomenon

116 You may find it helpful to look beyond your treatment and think about what you
senser phenomenon
act circumstance sen phen
phe.. sen
117 want to do when you feel well again. Many people find it helpful to set goals.
senser phenomenon
act goal
..nomenon
act circumstance
carr att
118 Setting goals gives them something to think about and work toward. Goals can
actor ben goal ini'or
act goal sen phen/circ act
119 also help people focus on what they want to achieve next week, next year, and
act circumstance
go/ph act/sen circ
120 into the future. As one man with cancer said,
sayer
121 *"I decided I would travel to Europe when my therapy was over. I used*
ver...
senser phenomenon act
actor circumstance
carrier attrib
122 *treatment time to research the countries I wanted to visit and read first-*
...
goal circ
act goal act goal
circ act goal
123 *person accounts written by other travelers. I bought a new camera and*
...
actor goal sen

actor
124 *figured out how to use it. I even brushed up on my French!"*
...biage
phen act goal
act goal

125 Goals can also help you get you through hard times. In fact, many cancer
ini'or act scope actor
126 patients have done much better than their doctor expected because they wanted
circ
phe sens circ
sen

127 to go to a wedding or meet their new grandchild.

phenomenon
act act goal

128 It is wise for people with cancer to "put their house in order." Think about making
car.. att ...rier sens phen
actor goal circ act
129 a will and talk about end-of-life choices with your loved ones. You may also want
sayer target circumstance act
goal
130 to put your photos into albums, write down your family history, and sort through
goal circ actor goal act
131 some of the things you own.
goal
attrib carr

132 Putting your house in order is not the same as giving up. In fact, it is a way that
carrier attribute tok value
act goal circ actor circ
133 people with cancer can live each day to the fullest and think about the future.

actor scope circ sen phen

134 These things make sense for everyone, sick or well.
actor goal circumstance
135 If you wait for tomorrow, tomorrow comes. If you don't wait for tomorrow,
circ act circ
act circ act circ
136 tomorrow comes. – Senegalese Proverb
act

137 **Advance Directives**

138 Advance directives are legal papers that allow you to decide ahead of time how
token value
sayer rec verbiage
sen phen..
139 you want to be treated when you are dying. They help your loved ones and
ini'or senser

...omenon
goal act circ
act
140 doctors know what to do if, and when, you can't tell them yourself.
phen circ
actor circ
verbiage say receiver

People with cancer face a lot of choices about the future. It's hard to talk about
carrier attrib att carrier
sayer
the end of your life.

verbiage
But when you do, you can have peace of mind. You will know you cared enough
circ carr attribute sens phen
say sens
to make hard choices for yourself, instead of leaving them for your loved ones
circ
act goal circ act goal circumstance
and health care providers.

Advance directives include:
carrier

A **will** to divide your money and things you own among your heirs
attri...
actor goal circumstance
attribute carr
A **living will** to let people know what kind of medical care you want if you are
...
sayer receiver verbiage
phenomenon sens circ
carr
close to death
...

attribute
A **durable power of attorney** to appoint a person (a "health care proxy") to
...
actor goal
actor
make medical decisions for you when you can't make them yourself
...

goal ben circ
act goal
A **trust** to give your money or things you own to someone else
...bute
actor goal circumstance
attribute carr
For more information, contact the Cancer Information Service at 1-800-4-
circ actor goal circ
CANCER (1-800-422-6237), by TTY (for deaf and hard of hearing callers) at 1-
circ
800-332-8615, or through the Internet at http://www.cancer.gov. Click on the
act goal

156 "Need Help?" button to send a message.
act goal
157 Once you finish treatment, you may expect life to return to the way it was before
circ sen phen
act goal act circ
carr att circ
158 cancer. In truth, it can take a while for life to settle down. This can be a hard
att carr tok value
159 time. While you adjust to life after treatment, you may find it helpful to read
circ sen phen
act circ act

160 Facing Forward: Life After Cancer Treatment.

goal
act circ
161 **Summing Up: Living Each Day**
actor scope

162 Living with cancer means not only looking at death but also how to live the rest
token value
actor circ behaver range circ act scope
163 of your life— whether it is long or short. Take care of daily duties and do things
act goal act scope
164 that are fun. Both are needed for a full life.
att carr circ
165 Many people who have cancer feel that living each day to the fullest means:
senser phenomenon
carrier attrib token
act scope
166 staying involved in the duties and pleasures of daily life

val...
carr attrib circumstance
167 returning to work if possible

...
actor circ
168 making plans for the future

...ue
actor goal circ

Appendix C

Living with Dying: Interview LD21

Age at Interview: 66
Sex: Male
Age at Diagnosis: 66
Background: Head of ship hydrodynamics research, married, 2 children
Brief outline: Developed symptoms in December 2001, diagnosed with oesophageal cancer in December 2002, treated with chemotherapy to shrink the tumour, followed by surgery in May 2003.

He doesn't want to know exactly how many years he has left to live.

1 Well I haven't asked them specifically how many years I could expect and I'm not
2 ducking that question but, do you know, I believe in adopting a very positive approach to
3 the whole thing. And I don't really need to be told [by the doctor] that it's one or two
4 years. I don't think I would welcome that, you know. (For me) To know that, at the
5 most, it may be five years downstream doesn't bother me a great deal but on the other
6 hand, when I say it doesn't bother me I mean it does (bother me), there's no doubt
7 about that. We all want to go on living as long as possible, but I can accept that, and I
8 believe my family can (accept that) but I'm not too sure I want to be told [by the doctor]
9 that it's a year away.
10 As I'm saying this to you I'm not too certain actually whether it would bother me or
11 not. I just haven't asked him, you know. I recognise the time will come when somebody
12 will be saying to me, "Well we can't really do anything for you now", and I'll have to
13 start thinking about 'Well am I going to stay at home or am I going to go into a
14 hospice?' well when that time comes I'm pretty confident I can deal with that and (I
15 can) cope with it okay. But I guess what it comes down to is I don't want to talk in
16 those terms until I've got to.

He suggests that doctors and nurses are now more willing to explain things than they were in the past.

17 Yes, well my main sources are from the medical people of course, whether it's my GP or
18 a consultant that I've seen, and before I go and (I) see anybody like that I write down,
19 that's important to stress that, (I) write down a list of questions and points I want to
20 raise with him and (I) make sure that they answer those questions.
21 One of the things I've found that whoever you're talking to, whether it's a GP, a
22 consultant or nurse, they're very willing to explain things (to you). I think that's a big
23 change, well we touched on this earlier before we started this interview, that's a big
24 change that's come about in recent years. The medical profession realises that it is
25 good, if the person wants it, (for the medical profession) to be as open as possible.

Suggests that there should be a named person who could help obtain information.

26 It's also helpful (for you) to have a mentor or a help person in that you find that so
27 many people are involved in your illness.
28 There's the GP, there's the cancer specialist - in my case there is a gastroenterology
29 specialist, there's the district nurse, there's the nutritionist, there's the dietitian, all
30 feeding you information.
31 If you're lucky and they approach you, or you know how to go out and (you) contact
32 them but there are lots of people don't know how to do that, and so that's once again
33 why I think this mentor would come in. Somebody who knows about all the contacts
34 and could point a sick person in the right direction if they haven't already been

35 contacted [by the medical experts?]

actor

36 Well unavoidably there are medical terms used [by medics] in the fact sheets and I'm
existent
goal
actor
carr
37 sure with many people it would be helpful to be able to discuss that with somebody and
att circ ca... attr ...rrier
sayer verb circ
38 get more information. Another point about this, I know when you're seeing a consultant
senser phenomenon
act goal circumstance
act scope
39 you can ask (the consultant) these questions but they're very busy people. They're very
token value carr
sayer receiver verbiage
40 specialised and I find they're very helpful. They are willing to give me their time but I'm
attrib sens phenomenon carr attribute carr
carr attribute actor ben goal
41 conscious of the fact that they are busy.
attribute
carr att

42 I don't like to think I'm wasting their time. I do put my questions (to them), but it
senser phenomenon say circ token
act goal
43 doesn't have to be a specialist, it could be a mentor who could get the information for
value token value
actor goal
44 you, maybe by reading it. They do have medical backgrounds and they could discuss it
carr ttrib sayer
ben actor
45 with you
circ

During chemotherapy he became depressed and had considered suicide.

How did you feel emotionally?

46 Emotionally (I feel) not too bad, not bad, (I feel) very weak physically. When we
carr attrib carr attribute circumstance
sayer
47 mention emotions, generally speaking, I've been able to cope with my emotions pretty
senser phenomenon
verbiage
48 well. During the chemotherapy treatment, during the last three weeks of it, when I was
circumstance
carr
49 very weakened, I did become quite depressed, even to the point of (me) saying that if it
carr attribute sayer verbiage
attribute
50 was suggested [to me by the doctors] that I have a fourth cycle of chemo, and bearing
senser (who?)
rec sayer verbiage
actor range
51 in mind I had three cycles, but I knew there was a possibility they might want to give
phen senser phenomenon
actor range senser phen
actor
52 me other cycles.

ben / goal

53 If they'd said to me, "You're going to need a fourth cycle" I was so depressed that I'd
54 probably have said "no way, I don't want it, I'm going to let the illness run its
55 course." Now it didn't come to that, they were satisfied with three cycles. I didn't even
56 have to discuss that with the oncologist.

Would you have discussed it with your wife and family?

57 I did (discuss it with my wife and family). I discussed it with my wife and my eldest
58 daughter. We're a very close-knit family, and my youngest daughter wasn't excluded,
59 (she) just wasn't here. I knew that my eldest daughter and wife would discuss it with
60 her. We've been very open about these things all along. I should say that at that stage
61 I had thought about suicide, you know, I had contemplated how I would go about it
62 if it came to it.

He is confident that when he reaches the last stage of his illness he will get enough morphine to control pain.

63 Generally speaking I found the pain control has been excellent. I've been lucky that
64 when I had one-day surgery, say an endoscopy, they put the needle in me, [they] gave
65 me a sedative, I would go to sleep. (I) Don't know anything about it. When I wake up
66 I'm fine. When it came to the operation I had the epidural. I went out very quickly and
67 (I) didn't know anything about it until I woke up in the Intensive Care Unit. After the
68 operation, the epidural was left in [by the medics] so I was being fed morphine.
69 Accidentally it came out and one evening I was in pain for several hours, nothing too
70 bad but I was in pain, and eventually they gave me a self administered morphine infuser
71 which went into my arm and I had a pump, I expect you've heard of this before?
72 You can't overdose or anything but I could give myself a shot of morphine when I
73 wanted it. They were willing to give me analgesics, paracetamol, Tramadol, whatever,
74 whenever I felt I needed it. If I was in pain I would ask (the doctor) for it. They kept

75 a very careful record of course of what I was having (for them)to make sure I didn't
range act goal
goal act actor
76 overdose, and generally speaking they gave me what I wanted to control the pain. So I
actor beni goal
ph..senser ...enomenon
77 would say my general experience has been that the pain control has been excellent. I
value token senser
carrier attribute
78 wouldn't worry about pain if I had to go through it again, it's been very good.
phen circumstance carr attribute
actor scope

And what do you think about the future, you feel quite confident then about the pain?

79 I do (feel quite confident about the pain), because during the last stages when you,
carr attribute circumstance
80 know there will be discomfort and pain around, I'm sure they'll give me enough
existent carr atti act ben/goal
actor
81 morphine or whatever it is to control the pain. If I ask for it I'll get it. I like to think
circumstance act goal senser
goal sayer verb
82 that and I do believe that will happen. I should say that if I find there is some
phen senser phen sayer ? verbiage
circumstance
senser phen
83 resistance, I mean I'm not asking anybody to overdose me or anything, but if I find that
senser phenomenon
sayer
receiver circumstance
actor goal senser
84 they're not controlling the pain to my satisfaction, well then I will be aggressive about it
carr attribute

phenomenon
actor goal circumstance
85 and [I will] push them. I'm not reluctant to do that.
actor goal carr attribute
actor

He doesn't believe in life after death and feels at peace with the idea that his body will decay and contribute to new life as part of a natural process.

86 My views are very simplistic. As a person with a scientific background I know about
carr attribute circumstance senser
87 conservation of energy. Energy is never lost within the Universe and I'm content to
phenomenon carr attribute
senser
88 believe that I'm all part of a much bigger thing. When I say bigger thing I don't mean
circumstance senser
phenomenon sayer verbiage
token value
89 any supernatural being, I don't know how the Universe started. I do believe that
phen senser phenomenon senser
90 sometime there will be a scientific explanation for it and I find that I'm sufficiently
phen senser phenomenon
carr attribute

91 fulfilled to think that okay, I will die and as I said earlier, I will be recycled. I will go on
senser phenomenon goal act
behaver circ token
sayer verbiage
92 to be a part of something else. Whatever it is, it doesn't really matter. I'm not thinking
value senser
value token

93 of reincarnation or anything like that. I don't believe I have another life hereafter.
phenomenon senser phenomenon
carr attribute
94 In fact, I don't want to go into this too much. I don't want to upset anybody.
senser phenomenon senser phenomenon
sayer ver phenom senser
95 These are very much my personal views which satisfy me, but the thought of a life
token value initiator
phenomenon senser
96 hereafter makes me shudder to be honest.
actor/goal
97 I don't want a life hereafter. No, no. I certainly don't want that.
senser phenomenon senser phenomenon

But from what you've said, because of your beliefs and because of the fulfilled life you've had, you can view the future with some sort of equanimity.

98 Yes I enjoy life. I don't want to die, who does? But I enjoy life very much. I'd like
senser ph senser phen sens phen senser phen senser
behaver
99 somebody to wave a magic wand and [someone to] say to me 'Your illness has gone
phenomenon
actor goal sayer rec verbiage
actor
100 away. You've got another ten, fifteen years ...'

carrier attribute

Discusses the complex moral issues involved in euthanasia.

When we had one of our breaks we talked a bit about the country's policy and in other countries on what we call assisted suicide and euthanasia and I wondered if you've got a view of that.

101 I find euthanasia very difficult. I feel I've made it clear that when I'm in the terminal
sen phenomenon sen phen
sayer verbiage
circumstance
carr attribute
102 stages, I would like to have an easy death. I mentioned pain, I'll refer to that again in
sayer verb sayer verb

senser phenomenon
carrier attribute
103 a minute. I would like an easy death and from that point of view I think I would
senser phenomenon circumstance senser
senser
104 welcome euthanasia.

phenomenon

105 Having said that I see all the complications of it and people who are at a stage of
senser phenomenon
carrier attribute
106 illness where they can't speak for themselves, a possibility of somebody wanting to get
senser phen
actor
sayer circumstance
107 rid of their relatives, that makes me very nervous so although on the one hand I would
attributor carr attribute senser
goal
108 like to see it to help me, I'm very hesitant about it, very hesitant.
phenomenon carr attribute
act goal

As a national policy.

109 As a national policy whereas in Sweden they go now and, is it Sweden? It's one of the
circ actor
110 Scandinavian countries isn't it and you can go there and (you can) arrange, that makes
actor actor attributor
111 me very uncomfortable you know. Yet on the other hand there was Diane isn't it, with
carr attribute existent
112 Motor Neurone disease and there, there was that poor women obviously wanted to die
existent
senser phen
actor
113 and nobody would do anything about it. It's a conflict, I don't know, I can't deal / deal
tok value senser actor/ senser
actor
114 with it, I don't know how you sort it out.
goal senser phenomenon
actor goal

He made sure his will was up -to date and left notes on family financial affairs.

115 I wanted to make sure that both my wife and I had up to date wills in place. I wanted
attributor att carrier attributor
carrier attribute
116 to make sure you know, as so often happens, wives don't get involved in the financial
attribute carr attribute
117 aspects very much.

118 My wife does (get involved) to some extent, I mean, numerically she's very good, she
carr attribute carr attribute actor
119 deals with accounts quite often, she's familiar with that side but she doesn't
range carr attribute senser
120 understand all the financial dealings of the family and I wanted to get that down on
phenomenon senser phenomenon
actor goal
121 paper so that she will have a good understanding with my daughters of what the
carr attr.... circumstance ....bute
token val..
122 arrangements are.

..ue

123 I also had felt it was essential to (for me to) get across to my wife and daughters the
senser phenomenon
ca.. attribute ..rrier
sayer circumstance
124 seriousness of the illness, you know, to the point of (me) saying (to them) that well it's
verbiage
sayer circ ver...
125 a serious operation. The cancer, the tumour can come back again. I feel sure that they
actor carr attribute
...biage senser
126 know sufficient about these things (for them) to understand that I felt for my own

phenomenon senser phenomenon
senser circum.....
127 benefit as much as theirs that they got that message.

..... stance phenomenon
actor goal

Key:

Processes Types		**Entities – Participant Roles**
Material process (red)	88	patient(s)
Mental process (turquoise)	95	doctor(s)
Relational process (blue)	88	other(s)
Behavioural process (lime)	7	illness
Verbal process (lavender)	42	other support
Existential Process (rose)	15	treatment